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Lung, and Colorectal Screening Among African American Men

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## Table of Contents

Front Cover .....	1
Standard Form 298 Documentation Page .....	2
Table of Contents .....	3
Introduction.....	5
Body .....	6
Statement of Work .....	6
Task 1 (a): Hire and train the case manager/retention coordinator and train the other study staff.....	7
Retention study procedures.....	7
Task 1 (b): Assign HFHS PLCO Cancer Screening Trial participants in the screening arm a socioeconomic status code and then assign them to the case manager/retention coordinator intervention group or to a control group.....	7
Figure 1: African American men in the PLCO Trial: developing and testing methods to increase retention.....	11
Task 1 (c): Implement the retention intervention .....	12
Task 1 (d): Conduct preliminary statistical analyses of the retention intervention .....	14
Task 1 (e): Conduct final statistical analyses of the retention intervention.....	14
Table 1: Educational characteristics of intervention group members vs. control group members .....	14
Table 2: Age characteristics of intervention group members vs. control group members .....	14
Table 3: Income characteristics of intervention group members vs. control group members .....	15
Table 4: Income characteristics of intervention group members by educational level .....	15
Table 5: Disposition of all calls made to the 301 intervention group participants through June 2001 .....	17
Table 6: Disposition of all calls made to the 301 intervention group participants through June 2001 (24 <sup>th</sup> study month) by month/year of call.....	19
Table 7: Disposition of all calls made to the 301 intervention group participants through June 2001 (24 <sup>th</sup> study month) by age group .....	17
Table 8: Disposition of all calls (reaching the participant vs. contact with another source) by participant age group.....	21
Table 9: Disposition of all calls made to the 301 intervention group participants through June 2001 (24 <sup>th</sup> study month) by participant income .....	21
Table 10: Disposition of all calls (reaching the participant vs. contact with another source) by participant income .....	22

Tasks 2 (a & b): (a) Conduct a literature search of existing instruments assessing cancer screening knowledge, attitudes, and beliefs among African American men (months 1-7) and (b) Use the results of the literature search to document the reliability/validity, purpose and conceptual approach of the literature search to document the reliability/validity, purpose and conceptual approach of each measurement instrument, and its cultural appropriateness for African American men .....	22
Task 2 (c): Use the results of the literature search to develop focus group questions (months 8-12). Step two: placing the identified potential survey items into a theoretical framework .....	27
Task 2 (d): Hold a focus group session to assess participants' perceptions of the developing measurement instrument and to garner ideas for new questions (month 13).....	35
Figure 2: Methods used in the focus group.....	36
Focus Group 1 Results .....	37
Table 11: Themes emerging from Focus Group 1 .....	38
Tasks 2 (e) - (i): Based on the focus group results, revise the measurement instrument. (f) Hold knowledge, attitudes, and beliefs among African American men (months 1-7) and (b) Use the results of the literature search to document the reliability/validity, purpose and conceptual approach of each measurement instrument, and its cultural appropriateness for African American men (months 1-7) .....	31
Focus Group 2 Results .....	77
Table 12: Themes emerging from Focus Group 2 .....	78
Key Research Accomplishments .....	90
Reportable Outcomes.....	92
Conclusions.....	93
References.....	96
Appendix Cover Sheet .....	99



## INTRODUCTION

### *SUBJECT AND PURPOSE OF THE RESEARCH*

The objective of this feasibility study is to identify innovative methods for increasing the retention of African American men in prostate cancer screening trials. Retention, while important for all groups, is especially critical for African American men, given their often low representation in clinical trials. The specific aims are to evaluate the efficacy of a retention intervention in retaining African American men in the screening arm of the Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial at the Henry Ford Health System site, and to develop a culturally appropriate measurement instrument to assess perceptions of screening for these cancers among older African American men.

### *SCOPE OF THE RESEARCH*

The study population consists of African American men aged 55 and older living in the Detroit area. Blocked randomization methods were used to assign the men to the retention intervention or control group. A retention coordinator provides intense follow-up to the men in the intervention group and will guide them through the PLCO Trial screening processes. Socioeconomic status is used as a covariate in later analyses.

It is hypothesized that men in the intervention group will show higher screening adherence rates than men in the control group. An instrument to assess cancer-screening perceptions among older African American men was developed using focus group techniques. The findings from this study will lay the foundation for randomized trials of the retention intervention (modified if necessary) in large prostate cancer screening or treatment trials involving African American men of different age groups. The psychometric properties of the measurement instrument could be tested for older and younger African American men. The instrument could then be used to help to identify potential study dropouts, who may need more intensive interventions in order to reduce attrition.

The retention study of African American men randomized to the intervention (screening) arm of the PLCO Trial began in June 1999 after five months of planning. In the retention study, 301 men have been randomly assigned to the intervention group and 300 men have been randomly assigned to the control group. The research protocol for the retention study has been approved by the Henry Ford Health System Institutional Review Board (HFHS IRB). An HFHS IRB continuation application was submitted and approved.

Retention study staff include Marvella E. Ford, Ph.D., Principal Investigator, Christine Cole Johnson, Ph.D., Co-Investigator, Michelle Jankowski, M.A.S., Statistician, Vernetta Randolph, Retention Coordinator, Danica Dixon-Macklin, Secretary, Toni Chociemski, Programmer and Mary Beavers, Data Manager. Consultants to the study include G. Marie Swanson, Ph.D. and Sally Vernon, Ph.D. On May 24, 1999 a Consultant Meeting was held with Drs. Swanson and Vernon. The meeting continued on May 25, 1999 with Dr. Vernon. The agenda for this meeting is included in Appendix A.

## BODY

### Statement of Work

#### African American Men in the PLCO Trial: Developing and Testing Methods to Increase Retention

##### *Task 1. Develop and test the case manager/retention coordinator intervention in the PLCO Cancer Screening Trial*

- (a) Hire and train the case manager/retention coordinator and train the other study staff (months 1-4)
- (b) Assign HFHS PLCO Cancer Screening Trial participants in the screening arm a socioeconomic status code and then assign them to the case manager/retention coordinator intervention group or to a control group (month 4)
- (c) Implement the retention intervention (months 5-28)
- (d) Conduct preliminary statistical analyses of the retention intervention (months 8-28)
- (e) Conduct final analyses (months 28-30)

##### *Task 2. Develop a culturally appropriate measurement instrument to assess cancer screening perceptions of African American men*

- (a) Conduct a literature search of existing instruments assessing cancer screening knowledge, attitudes, and beliefs among African American men (months 1-7)
- (b) Use the results of the literature search to document the reliability/validity, purpose and conceptual approach of each measurement instrument, and its cultural appropriateness for African American men (months 1-7)
- (c) Use the results of the literature search to develop focus group questions (months 8-12)
- (d) Hold a focus group session to assess participants' perceptions of the developing measurement instrument and to garner ideas for new questions (month 13)
- (e) Based on the focus group results, revise the measurement instrument (months 14-20)
- (f) Hold a focus group session to assess participants' perceptions of the revised measurement instrument (month 21)
- (g) Incorporate participants' suggestions into a further refinement of the instrument (months 22-30)
- (h) Conduct statistical analyses of the pilot study results (months 26-27)
- (i) Revise and refine the final measurement instrument, based on the pilot study results (months 28-30)

Progress related to each task in the Statement of Work is described in the following sections of the annual report.

*Task 1 (a): Hire and train the case manager/retention coordinator and train the other study staff (months 1-4)*

A case manager/retention coordinator was hired and began training in month 1. However, she took another position at the end of month 2. A search was conducted for another case manager/retention coordinator, who was hired and trained in months 4-6.

*Task 1 (b): Assign HFHS PLCO Cancer Screening Trial participants in the screening arm a socioeconomic status code and then assign them to the case manager/retention coordinator intervention group or to a control group (month 4)*

Randomization (Figure 1) and other study procedures took place starting in month 6, once the case manager/retention coordinator was fully trained. Once individuals were identified as study participants, their home addresses were geocoded using census block group methods. Geographic information system (GIS) technology is an established computer mapping and analysis technology capable of linking geographic with demographic information.<sup>1</sup> Using GIS technology, Census was used to assign each study participant the average household income in the block-group of residence (a subdivision of a census tract representing a city block).<sup>2</sup> This process has been found to be a valid and reliable method of assigning census-based characteristics such as socioeconomic status to study participants.<sup>2-4</sup> Once geocoded, each case was assigned an income level code (low or moderate-to-high) based on Federal Register poverty guidelines and adjusted for household size. Low income level was defined as an annual household income < 1.5 times the poverty level, adjusted for household size, and moderate-to-high income level was defined as an annual income  $\geq$  1.5 times the poverty level, adjusted for household size.

Part of the retention coordinator's training consisted of contacting a large number of agencies serving community adults, particularly older adults, to develop a resource file of available community resources. These resources are shared with the study participants during the course of the study, as one of the study goals is to serve as an information clearinghouse for participants. In this manner, the case manager/retention coordinator addresses competing needs of the participants that may function to prevent them from adhering to their PLCO screening tests. The study procedures are documented in the following paragraphs. Study staff whose salaries appear on the retention study budget include: Marvella E. Ford, Ph.D., Principal Investigator; Vernetta Randolph, Retention Coordinator/Case Manager; Michelle Jankowski, M.A.S., Biostatistician; and Toni Chociemski, Programmer.

#### Retention Study Procedures

- 1) A data manager generated a list of all African American males in the PLCO Trial Intervention Arm (n=601).
  - ☐ This list only contained the names of active participants. It did not include people who were being tracked or lost to follow-up, deceased people, or people who have refused all further contact by PLCO staff.
- 2) The statistician on the retention study, Ms. Michelle Jankowski, randomized individuals on the list to Control or Intervention groups.
- 3) The Retention Coordinator, Ms. Vernetta Randolph, generated a list of study participants by Control and Intervention groups.
- 4) The group assignment information was forwarded to PLCO staff and a data manager generated separate Overview Sheets for each participant. The information on the Overview Sheets for each participant includes:
  - ☐ Demographic information
  - ☐ Study identification number
  - ☐ Screening examinations received (*based on study year*)
  - ☐ Telephone number(s) where participants can be reached

- 5) Before the retention study began:
  - a) Ms. Jankowski developed an Access database to record telephone calls and specific interventions for each participant.
  - b) Each participant's status (DOD-I or DOD-C) was inserted into the SMS scheduling notes.
- 6) The retention study participants were pulled from the PLCO Cancer Screening Trial database in July 1999, when the intervention was implemented.

These study procedures were further refined in the following manner.

- 1) Calls to the DOD-I and DOD-C study participants are made routinely (at least once per month for the DOD-I participants) by the Retention Coordinator (Ms. Randolph). The participants are called at approximately the same time of the month each month. That is, the participants scheduled to receive a call early in the month are called from the 1<sup>st</sup> through the 10<sup>th</sup> of each month. The participants scheduled to receive a call in the middle of the month are called from the 11<sup>th</sup> through the 20<sup>th</sup> of each month. Finally, the participants scheduled to receive a call during the latter part of the month are called from the 21<sup>st</sup> through the end of each month.
- 2) Approximately five days after the last scheduled call dates, Ms. Randolph, the Retention Coordinator, batches the call sheets and gives them to the data management staff. The schedule for this is as follows:
  - a) The call sheets for the first of the month calls are attached to a DOD cover sheet and are then given to the data management staff by Ms. Randolph by the 15<sup>th</sup> of each month.
  - b) The call sheets for the middle of the month calls are attached to a DOD cover sheet and are then given to the data management staff by Ms. Randolph by the 25<sup>th</sup> of each month.
  - c) The call sheets for the end of the month calls are attached to a DOD cover sheet and are then given to the data management staff by Ms. Randolph by the 5<sup>th</sup> of the following month.
- 3) The data management staff verify the number of call sheets given to them by Ms. Randolph. If there are any discrepancies the call sheets are returned to Ms. Randolph for correction.
- 4) Data management staff enter the calls into the study database and then return the call sheets to Ms. Randolph in approximately one week. Prior to returning the call sheets, the data manager verifies/documents, on the DOD cover sheet, the number of call sheets returned.

The DOD data cover sheet and the telephone call sheet are shown in the following pages.

## DOD STUDY DATA COVER SHEET

**DOD Study Retention Coordinator:** \_\_\_\_\_

**DOD Study Data Manager:** \_\_\_\_\_

	<b>Date</b>	<b>Number</b>	<b>Initials</b>
Call Sheets Given to Data Manager			
Calls Entered into DOD Study database			
Call Sheets Returned to DOD Study Retention Coordinator			

## **“DOD Study: Retaining African American Men in the PLCO Cancer Screening Trial”**

[illegible]

**Final Outcome:**\_\_\_\_\_

## Disposition

**Codes:**

**Final Outcome Codes:****Person Spoken With:**

**Day of the Week:**

NA	No answer
AM	Answering machine
CB	Asked to call back
Busy	Busy
NPUB	Changed to non-published
WN	Wrong number
DISC	Disconnected

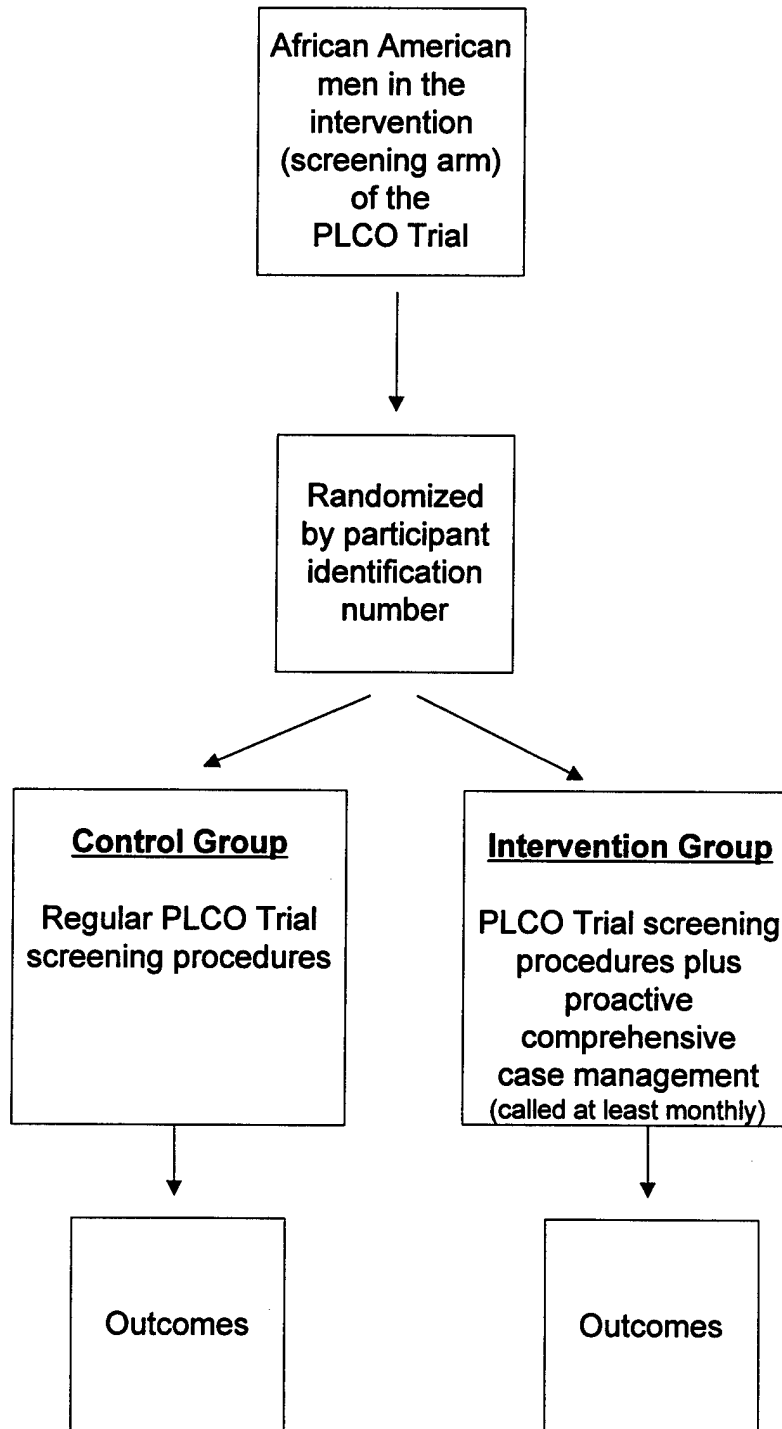
1 Deceased  
2 Language barrier  
3 Refusal  
4 Unavailable  
5 Cannot trace  
6 Interview complete

1 Participant  
2 Spouse  
3 Child  
4 Other family member  
5 Unknown person

- 1 Sunday
- 2 Monday
- 3 Tuesday
- 4 Wednesday
- 5 Thursday
- 6 Friday
- 7 Saturday

**Figure 1**

**African American Men in the PLCO Trial:  
Developing and Testing Methods to  
Increase Retention**



*Task 1 (c): Implement the retention intervention (months 5-28)*

Due to the turnover in the case manager/retention coordinator position, the retention intervention began in July 1999. Retention intervention procedures related to scheduling are described in the paragraphs below. In addition, the investigators developed telephone scripts for each type of telephone contact, for use by the case manager/retention coordinator. These scripts are included in Appendix B. The Retention Coordinator (Ms. Randolph) was trained in the administering of these scripts during months 4-6. These scripts are tailored based on the following variables: each participant's study year; the types of exams each participant is scheduled to receive each year; and the extent to which each participant adhered to their scheduled screening exams in the previous year. Tailoring the scripts for each study participant allows barriers counseling specific to each individual to be conducted.

- A. Personal Identification (PID) numbers for each participant were printed on a listing generated by the PLCO data manager.
  - These PID numbers were used to generate an Annual Study Update (ASU) that is mailed to participants enrolled in the study.
  - Also from the PID listing, a participant overview form was generated. This form identifies which screening tests are needed.
- B. The PLCO data manager files the participant overview sheets and contact sheets by (a) study year, (b) randomization date, and (c) alphabetical order.
- C. The PLCO data manager gives Ms. Randolph the retention study participant overview sheets and contact sheets for the retention study participants with an upcoming annual screening examination. Retention study staff use a temporary filing system similar to that described in (B) to store documents on a temporary basis.
- D. Ms. Randolph checks the participant overview sheet to see which study year the person is in (e.g. T0, T1, and etc.) and she identifies whether the person is in the retention study intervention (DOD-I) or retention study control group (DOD-C).
- E. Ms. Randolph stamps the upper right corner of the participant overview sheet using a stamp inscribed DOD-I or DOD-C.
  - DOD-I: Intervention Group. For this group, Ms. Randolph places a call to each participants' home once a month to schedule screening appointments and address any human services needs. (At the start of the project, Ms. Randolph let the participant and his spouse/mate know that she would call the home monthly to talk with the participant.)
  - When establishing contact with the participant, Ms. Randolph asks to speak with the participant's spouse/mate and asks whether she/he has any human services needs.
  - DOD-C: Control Group. For this group, Ms. Randolph only places a call to each participant's home to schedule screening appointments when needed.
  - Note: If a DOD-I participant had already received a scheduling call from PLCO at the beginning of the retention study, Ms. Randolph did not call the participant until the next month.
- F. For the DOD-C group participants, Ms. Randolph uses the standard PLCO scheduling script.
- G. For the DOD-I group participants, Ms. Randolph uses the enhanced scheduling script.
- H. Ms. Randolph schedules the appropriate screening appointment(s) using the PLCO scheduling method and stamps/writes DOD-I (Intervention) or DOD-C (Control) on the name line of the schedule form in the right corner.
- I. Ms. Randolph records all interactions with DOD-I participants in an Access database checklist. She enters text summarizing each discussion with each study participant in a Microsoft Word file. This information is updated daily.



- J. At the end of each business day, or prior to 7:30 a.m. of the next business day, Ms. Randolph gives the completed contact forms and overview sheets to the PLCO screening appointment schedulers.
- K. On Tuesdays, the PLCO screening appointment schedulers review all contact forms and overview sheets and once the information has been reviewed, the 'final' sheets are given to the PLCO secretaries, who prepare a typed schedule and add DOD-I and DOD-C to the name line, when appropriate. PLCO office staff instruct PLCO clinic staff to ignore the DOD-I/ DOD-C (across from participants' name) information that is added to the appointment schedule. The PLCO secretaries make a copy of the typed appointment schedule for Ms. Randolph. Ms. Randolph ignores all non-retention study participants when making her reminder calls for scheduled PLCO screening appointments, and therefore only calls retention study participants.
- L. The PLCO secretaries prepare 2 copies of screening appointment reminder letters and send one copy to the participant. Participants are instructed to call the general PLCO number to cancel or reschedule appointments. (*See N*) The other copy is placed in the participant's file along with the contact sheet and overview sheet. This information is filed in the PLCO scheduling office.
- M. The day before each retention study participant's scheduled screening appointment, Ms. Randolph places a reminder call to the retention study participant.
- N. If a retention study participant cancels his appointment during the reminder call, Ms. Randolph notes this information on her typed appointment list and notifies the PLCO screening appointment schedulers of the cancellation.
- O. Cancellations: The PLCO screening appointment schedulers contact the PLCO screening clinics regarding ALL cancelled appointments.
  - ☐ Ms. Randolph re-schedules all retention study participant appointments.
  - ☐ When a participant calls the general PLCO number to cancel a screening appointment, the PLCO screening appointment schedulers do not re-schedule the appointment, which is different than the PLCO process. Instead, the PLCO screening appointment schedulers notify Ms. Randolph, who then contacts the retention study participants to re-schedule their annual screening appointments.

Originally, Ms. Randolph was only going to conduct scheduling calls for the participants assigned to the intervention group. However, one of the retention study's co-investigators pointed out the fact that a potential source of bias, "interviewer bias", would be reduced if Ms. Randolph, the Retention Coordinator, scheduled annual exams for participants in the intervention group and for participants in the control group. Therefore, scheduling procedures in the retention study were integrated with existing scheduling procedures in the PLCO Trial.

### **Retention Study Intervention:**

In addition to scheduling annual screening appointments for the intervention group and control group retention study participants, Ms. Randolph proactively calls the DOD-I participants once a month. During each call, she ascertains participants' human services/ information needs (e.g., health insurance information, physician referral, health care condition-specific information, and local physicians who will see uninsured patients). Ms. Randolph leaves voice mail messages including her office telephone number for the DOD-I participants with whom she is unable to speak personally after repeated attempts to speak with them. When Ms. Randolph leaves these messages, she reiterates the fact that she is serving as a resource person for the participant.

*Task 1 (d): Conduct preliminary statistical analyses of the retention intervention (months 8-28)*

These findings were reported in the Annual Report.

*Task 1 (e): Conduct final analyses.*

Group comparisons between two categorical variables such as group and education were conducted using likelihood ratio chi-square tests. Group comparisons of mean age were tested using the Student's t-test. Tables 1-3 show that, as was the goal with the randomization process used in the present study, no statistically significant differences in educational level, age or income were found between the intervention group and the control group.

Table 1. Educational Characteristics of Intervention Group Members vs. Control Group Members

	Intervention Group*	Control Group	p-value**
	(n=299)	(n=300)	
	n (%)	n (%)	
Education			0.65
<8 years	17 (5.7)	14 (4.7)	
8-11 years	56 (18.7)	65 (21.7)	
12 years or completed high school	67 (22.4)	63 (21.0)	
Post high school training other than college	24 (8.0)	35 (11.7)	
Some college	79 (26.4)	71 (23.7)	
College graduate	22 (7.4)	24 (8.0)	
Postgraduate	34 (11.4)	28 (9.3)	

\*Some cases were missing data on the education variable

\*\*Based on a chi-square test

Table 2. Age Characteristics of Intervention Group Members vs. Control Group Members

	Intervention Group	Control Group	p-value*
	(n=301)	(n=300)	
	n (s.d.)	n (s.d.)	
Mean Age (s.d.)	66.5 (6.3)	66.6 (6.0)	0.84

\*Based on a student's t-test

Table 3. Income Characteristics of Intervention Group Members vs. Control Group Members

	Intervention Group*	Control Group*	p-value**
	(n=292)	(n=292)	
	n (%)	n (%)	
Income			0.79
Moderate-to-High	205 (70.2)	202 (69.2)	
Low	87 (29.8)	90 (30.8)	

\*Some cases were missing data on the income variable

\*\*Based on a chi-square test

Due to the randomized trial design of the retention intervention and the fact that the intervention will be continued in Phase II, results do not show the final outcome of PLCO Trial screening adherence based on retention intervention or control group status. This information will be analyzed at the conclusion of Phase II. Instead, Tables 4-10 show the results of analyses of the retention intervention by the study covariates of income, education and age.

Table 4 shows that among the intervention group participants, an inverse relationship was found between level of education (<8 years through post-college training) and income level (moderate-to-high or low).

Table 4. Income Characteristics of Intervention Group Participants by Educational Level

	<8 Years	8-11 Years	12 Years or H.S.*	Post- H.S. (NoColl.)**	Some Coll.^	Coll. Grad^^	+Coll. Grad&	p-value
	n (col %)	n (col %)	n (col %)	n (col %)	n (col %)	n (col %)	n (col %)	
Income								0.0013
Mod.-to-High	19 (61.3)	70 (59.3)	87 (68.5)	39 (72.2)	100 (67.6)	37 (84.1)	53 (88.3)	
Low	12 (38.7)	48 (40.7)	40 (31.5)	15 (27.8)	48 (32.4)	7 (15.9)	7 (11.7)	
Total	31 (100)	118 (100)	127 (100)	54 (100)	148 (100)	44 (100)	60 (100)	

\*H.S. = High school diploma or equivalent

\*\*Post-H.S. (NoColl.) = Post-high school degree but no college degree

^SomeColl. = Some college training but no college degree

^^Coll.Grad = College graduate

&+CollGrad = College degree plus at least some post-graduate training

Table 5 shows data related to the disposition of all calls made to the 301 intervention group participants through June 2001 (24<sup>th</sup> study month). It is important to note that the "Intro. Call" (Introductory Call) refers to the first call made to a participant during which some type of contact was made with the participant (either directly or via an answering machine, spouse, other family member, etc.), regardless of the actual month in which the call was made. The "1<sup>st</sup> Month Call" refers to calls made 30 days past the date of the "Intro. Call" (but less than 60 days past this date). The "2<sup>nd</sup> Month Call" refers to calls made 60 days past the date of the "Intro. Call" (but less than 90 days past this date); the "3<sup>rd</sup> Month Call" refers to calls made 90 days past the date of the "Intro. Call" (but less than 1200 days past this date), etc. Thus, many "Intro. Calls" occurred after July 1999, when the retention intervention began and Ms. Randolph, the Retention Coordinator, first began to make monthly calls to study participants. As may be seen in Table 5, each month, participants are contacted at a rate greater than once call per month per participant. Thus, Ms. Randolph often makes multiple calls to the study participants during each month. Table 5 also shows that the majority of study participants have not yet reached the time period of receiving their "24<sup>th</sup> Month Calls".

Table 5. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24<sup>th</sup> Study Month)

Type of Call	Call Disposition					
	Answering Machine	Spouse	Unknown Person	Participant	Other Family Member	Total
	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Intro. Call	182 (32.1)	32 (5.6)	111 (19.6)	233 (41.1)	9 (1.6)	567 (100)
1 <sup>st</sup> Month Call	118 (25.1)	42 (8.9)	107 (22.7)	201 (42.7)	3 (0.6)	471 (100)
2 <sup>nd</sup> Month Call	118 (26.5)	27 (6.0)	81 (18.2)	215 (48.2)	5 (1.1)	446 (100)
3 <sup>rd</sup> Month Call	120 (29.7)	28 (6.9)	64 (15.8)	188 (46.4)	5 (1.2)	405 (100)
4 <sup>th</sup> Month Call	129 (31.9)	22 (5.4)	64 (15.8)	184 (45.4)	6 (1.5)	405 (100)
5 <sup>th</sup> Month Call	91 (25.2)	19 (5.3)	62 (17.2)	186 (51.5)	3 (0.8)	361 (100)
6 <sup>th</sup> Month Call	114 (27.2)	24 (5.7)	68 (16.2)	209 (49.9)	4 (1.0)	419 (100)
7 <sup>th</sup> Month Call	104 (26.1)	19 (4.8)	55 (13.8)	217 (54.5)	3 (0.8)	398 (100)
8 <sup>th</sup> Month Call	123 (28.6)	14 (3.3)	80 (18.6)	210 (48.8)	3 (0.7)	430 (100)
9 <sup>th</sup> Month Call	168 (31.4)	20 (3.7)	89 (16.7)	255 (47.8)	2 (0.4)	534 (100)
10 <sup>th</sup> Month Call	145 (32.9)	19 (4.3)	68 (15.4)	204 (46.3)	5 (1.1)	441 (100)
11 <sup>th</sup> Month Call	154 (31.6)	13 (2.7)	60 (12.3)	246 (50.5)	14 (2.9)	487 (100)
12 <sup>th</sup> Month Call	157 (34.0)	18 (3.9)	48 (10.4)	228 (49.3)	11 (2.4)	462 (100)
13 <sup>th</sup> Month Call	181 (31.8)	26 (4.6)	45 (7.9)	295 (51.7)	23 (4.0)	570 (100)
14 <sup>th</sup> Month Call	118 (28.2)	25 (6.0)	36 (8.6)	229 (54.8)	10 (2.4)	418 (100)
15 <sup>th</sup> Month Call	86 (23.0)	20 (5.4)	29 (7.7)	221 (59.1)	18 (4.8)	374 (100)
16 <sup>th</sup> Month Call	93 (25.3)	14 (3.8)	19 (5.2)	236 (64.1)	6 (1.6)	368 (100)
17 <sup>th</sup> Month Call	78 (24.7)	11 (3.5)	17 (5.4)	194 (61.4)	16 (5.0)	316 (100)
18 <sup>th</sup> Month Call	99 (25.3)	19 (4.9)	35 (8.9)	224 (57.1)	15 (3.8)	392 (100)
19 <sup>th</sup> Month Call	116 (28.2)	18 (4.4)	20 (4.8)	238 (57.8)	20 (4.8)	412 (100)
20 <sup>th</sup> Month Call	102 (26.7)	15 (3.9)	19 (5.0)	222 (58.1)	24 (6.3)	382 (100)
21 <sup>st</sup> Month Call	68 (21.6)	17 (5.4)	4 (1.3)	216 (68.5)	10 (3.2)	315 (100)
22 <sup>nd</sup> Month Call	76 (24.7)	24 (7.8)	12 (3.9)	186 (60.4)	10 (3.2)	308 (100)
23 <sup>rd</sup> Month Call	88 (36.5)	15 (6.2)	6 (2.5)	118 (49.0)	14 (5.8)	241 (100)
24 <sup>th</sup> Month Call	12 (44.5)	3 (11.1)	0 (0)	11 (40.7)	1 (3.7)	27 (100)
Total Calls	2840 (28.5)	504 (5.1)	1199 (12.1)	5166 (51.9)	240 (2.4)	9949 (100)

Table 6 shows the disposition of all calls made to the 301 intervention group participants through June 2001 (24<sup>th</sup> Study Month) by month/year of call. As may be seen in this table, in the majority of cases, Ms. Randolph, the Retention Coordinator, is most likely to speak directly with the study participant. However, in cases in which the participant is not available, Ms. Randolph leaves messages with an answering machine. The scripts used when an answering machine is encountered or when the participant is not available are included in Appendix B. In each case, whenever a message is left, Ms. Randolph states her name, the name of the PLCO Cancer Screening Trial, and indicates that she is the participant's resource person. She also provides her telephone number at work and lets the participant know that he can call her at anytime if he or a family member, friend or neighbor would like information on any topic related to health or human services. Thus, whether a participant is contacted directly or receives a message from Ms. Randolph, the concept of having Ms. Randolph as a resource person is reinforced. Additionally, Ms. Randolph repeatedly attempts to speak directly with each participant each month, even if she has previously left a message for the participant during the same month.

Table 6. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24<sup>th</sup> Study Month) by Month/Year of Call

Call Disposition						
	Answering Machine	Spouse	Unknown Person	Participant	Other Family Member	Total
	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Type of Call						
07/1999	96 (30.0)	23 (7.2)	64 (20.0)	136 (42.5)	1 (0.3)	320 (100)
08/1999	142 (29.7)	33 (6.9)	101 (21.1)	199 (41.5)	4 (0.8)	479 (100)
09/1999	110 (28.1)	30 (7.7)	86 (22.0)	161 (41.2)	4 (1.0)	391 (100)
10/1999	115 (29.0)	23 (5.8)	69 (17.4)	186 (46.8)	4 (1.0)	397 (100)
11/1999	111 (27.7)	28 (7.0)	66 (16.5)	193 (48.1)	3 (0.7)	401 (100)
12/1999	130 (31.4)	21 (5.1)	57 (13.8)	202 (48.7)	4 (1.0)	414 (100)
01/2000	105 (25.4)	21 (5.1)	76 (18.4)	207 (50.1)	4 (1.0)	413 (100)
02/2000	102 (28.2)	21 (5.8)	51 (14.1)	187 (51.6)	1 (0.3)	362 (100)
03/2000	111 (24.9)	22 (4.9)	84 (18.8)	222 (49.8)	7 (1.6)	446 (100)
04/2000	149 (32.8)	17 (3.3)	78 (17.1)	211 (46.4)	2 (0.4)	455 (100)
05/2000	148 (30.0)	19 (3.9)	74 (15.0)	250 (50.7)	2 (0.4)	493 (100)
06/2000	167 (31.3)	21 (4.0)	78 (14.6)	253 (47.5)	14 (2.6)	533 (100)
07/2000	181 (34.9)	16 (3.1)	62 (11.9)	247 (47.6)	13 (2.5)	519 (100)
08/2000	166 (35.4)	22 (4.7)	31 (6.6)	231 (49.2)	19 (4.1)	469 (100)
09/2000	134 (29.4)	15 (3.3)	46 (10.1)	245 (53.9)	15 (3.3)	455 (100)
10/2000	99 (25.1)	31 (7.8)	32 (8.1)	222 (56.2)	11 (2.8)	395 (100)
11/2000	93 (24.1)	18 (4.7)	24 (6.2)	233 (60.3)	18 (4.7)	386 (100)
12/2000	57 (17.0)	12 (3.6)	17 (5.1)	243 (72.5)	6 (1.8)	335 (100)
01/2001	105 (25.2)	11 (2.6)	33 (7.9)	246 (59.0)	22 (5.3)	417 (100)
02/2001	118 (29.4)	21 (5.2)	19 (4.7)	228 (56.7)	16 (4.0)	402 (100)
03/2001	117 (29.2)	15 (3.8)	22 (5.5)	230 (57.5)	16 (4.0)	400 (100)
04/2001	60 (18.2)	18 (5.5)	11 (3.3)	217 (66.0)	23 (7.0)	329 (100)
05/2001	100 (28.7)	20 (5.7)	4 (1.2)	216 (62.1)	8 (2.3)	348 (100)
06/2001	124 (31.8)	28 (7.2)	14 (3.6)	201 (51.5)	23 (5.9)	390 (100)
Total Calls	2840 (28.5)	504 (5.1)	1199 (12.1)	5166 (51.9)	240 (2.4)	9949 (100)

Table 7 shows the disposition of all calls made to the 301 intervention group participants through June 2001 (24<sup>th</sup> Study Month) by age group. The data shown indicate that among participants aged <65 years, 44% of participants have been contacted directly by Ms. Randolph. In contrast, among participants aged 74+ years, 63% of participants have been contacted directly by Ms. Randolph. These findings suggest that the older participants may be less likely to be working and more likely to be retired and thus available to speak with Ms. Randolph, compared with the younger participants. Thus, the older participants appear to have a higher likelihood of being at home when Ms. Randolph calls each month. Ms. Randolph works until 8:00 p.m. one night per week as well as one Saturday per month, in an attempt to reach the participants who are difficult to reach during regular business hours.

Table 7. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24<sup>th</sup> Study Month) by Age Group

	Call Disposition					
	Answering Machine	Spouse	Unknown Person	Participant	Other Family Member	Total
	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Age Group						
<65 years	1486 (32.6)	197 (4.3)	687 (15.1)	2007 (44.0)	184 (4.0)	4561 (100)
65-74 years	1078 (26.1)	232 (5.6)	399 (9.7)	2366 (57.3)	51 (1.3)	4126 (100)
>74 years	276 (21.9)	75 (5.9)	113 (9.0)	793 (62.8)	5 (0.4)	1262 (100)
Total	2840 (28.5)	504 (5.1)	1199 (12.1)	5166 (51.9)	240 (2.4)	9949 (100)

Table 8 provides confirmation that a statistically significant difference was found in the likelihood of speaking with the participant directly among younger vs. older participants. As may be seen, younger participants (aged <65 years) have been spoken with directly in 44% of all calls made by Ms. Randolph. In contrast, older participants (aged 74+ years) have been spoken with directly in 63% of all calls made by Ms. Randolph.



Table 8. Disposition of All Calls (Reaching the Participant vs. Contact with Another Source) by Participant Age Group

	Call Disposition		
	Participant	Other Contact	p-value
	n (row %)	n (row %)	
Age Group			<0.001
<65 years	2007 (44.0)	2554 (56.0)	
65-74 years	2366 (57.3)	1760 (42.7)	
>74 years	793 (62.8)	469 (37.2)	
Total	5166 (51.9)	4783 (48.1)	

Table 9 shows the disposition of all calls made to the 301 intervention group participants through June 2001 (24<sup>th</sup> Study Month) by participant income. The data in this table indicate that among individuals with moderate-to-high incomes, 51% of calls occurred in which Ms. Randolph spoke directly with the study participant. This percentage was similar (55%) among participants with low incomes.

Table 9. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24<sup>th</sup> Study Month) by Participant Income

	Answering Machine	Spouse	Unknown Person	Participant	Other Family Member	Total
	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Income						
Moderate-to-High	1995 (29.6)	329 (4.9)	827 (12.3)	3463 (51.4)	118 (1.8)	6732 (100)
Low	660 (23.3)	162 (5.7)	334 (11.8)	1560 (55.0)	119 (4.2)	2835 (100)
Total	2655 (27.8)	491 (5.1)	1161 (12.1)	5023 (52.5)	237 (2.5)	9567 (100)

Table 10 shows the disposition of all calls (reaching the participant vs. contact with another source) by participant income. Although the data shown in Table 10 are statistically significant, they are likely not socially meaningful, due to the similarity in row percentages of contact type by participant income.

Table 10. Disposition of All Calls (Reaching the Participant vs. Contact with Another Source) by Participant Income

	Participant	Other Contact	p-value
	n (row %)	n (row %)	
Income			<0.0013
Moderate-to-High	3463 (51.4)	3269 (48.6)	
Low	1560 (55.0)	1275 (45.0)	
Total	5023 (52.5)	4544 (47.5)	

*Tasks 2 (a & b): (a) Conduct a literature search of existing instruments assessing cancer screening knowledge, attitudes, and beliefs among African American men (months 1-7) and (b) Use the results of the literature search to document the reliability/validity, purpose and conceptual approach of each measurement instrument, and its cultural appropriateness for African American men (months 1-7)*

Three steps were involved in making progress toward developing a culturally appropriate measurement instrument to assess perceptions of cancer screening among African American men. First, a literature search on this topic was conducted. Potential instrument items that were apparent from this literature search are shown in the following section. The second step involved placing the identified items into a theoretical framework. In this step, the items were grouped into the explanatory framework of the Preventive Health Model.<sup>5</sup> This model, which incorporates concepts from the Health Belief Model,<sup>6</sup> the Theory of Reasoned Action,<sup>7</sup> and the Social Cognitive Theory.<sup>8</sup> In the third step, a smaller subset of actual focus group items were derived from the list of potential focus group items identified through the literature search.

#### *Step One: Conducting a Literature Search to Identify Potential Survey Items*

Focus group items that resulted from this literature search are listed in the following paragraphs of the report. The source of each set of items is identified.

**SOURCE: Attitudes of African Americans Regarding Screening for Prostate Cancer. (Robinson and Haynes 1996)<sup>9</sup>**

**ITEMS:**

What do you think would help to motivate Black men to get screened for \_\_\_\_ cancer?  
What do you think are the most important reasons many African American men choose not to get screened for \_\_\_\_ cancer?  
To what extent do you think that fear and mistrust of the medical establishment will keep Black men from getting screened for \_\_\_\_ cancer?  
Do you think that some men fear the exam or test for \_\_\_\_ cancer because it is associated with homosexuality?

**SOURCE: Evaluating Focus Group Data: Barriers to Screening for Prostate Cancer Patients. (Dale 1998)<sup>10</sup>**

**ITEMS:**

Does the fact that your doctor is a male/female affect your decision to get prostate cancer screening?  
Would embarrassment keep you from getting screened for prostate cancer?  
What kinds of things - good or bad - have you heard about the tests for prostate cancer?  
Would these things keep you from getting tested for prostate cancer?

**SOURCE: Knowledge, Beliefs, and Prior Screening Behavior Among Blacks and Whites Reporting For Prostate Cancer Screening. (Demark-Whahnefried, Strigo, Catoe, Conway, Brunetti, Rimer, and Robertson 1995)<sup>11</sup>**

**ITEMS:**

Do you know someone who has had \_\_\_\_ cancer?  
Is it possible to have \_\_\_\_ cancer without having symptoms of this disease?  
What motivated you to get checked for \_\_\_\_ cancer?

**SOURCE: The Role of Focus Groups in Health Education for Cervical Cancer among Minority Women. (Dignan, Michielutte, Sharp, Bahnson, Young, and Beal 1990)<sup>12</sup>**

**ITEMS:**

Do you think that some people choose not to get screened for \_\_\_\_ cancer because they cannot afford treatment if \_\_\_\_ cancer were found?  
Do you have difficulty now in getting regular health care? What are some of the problems you are facing? (Ex: waiting time to get an appointment; waiting time at doctor's office)

**SOURCE: Breast Cancer Screening: Racial/Ethnic Differences in Behaviors and Beliefs. (Friendman, Webb, Weinberg, Lane, Cooper, and Woodruff 1995)<sup>13</sup>**

**ITEMS:**

What do you think is your risk of developing \_\_\_\_ cancer, compared to other men of your age?  
Do you think that being older or being African American affects your chances of getting \_\_\_\_ cancer?  
Does fear keep you from getting screened for \_\_\_\_ cancer?  
What are some of your fears related to \_\_\_\_ cancer screening?

Do you think that people don't get \_\_\_\_\_ cancer screening because they just never get around to it?

Do you think that some people avoid getting screened for \_\_\_\_\_ cancer because they are afraid to think about cancer?

Do you agree that there is little hope for people with \_\_\_\_\_ cancer?

Do you think \_\_\_\_\_ cancer can be cured if it is found early enough?

**SOURCE: Cancer Screening among African American Women: Their Use of Tests and Social Support. (Kang, Bloom, and Romano 1994)<sup>14</sup>**

**ITEMS:**

Do you think that:

Being married

Being a church member

Being a member of other types of organizations

Being encouraged by relatives and friends

would influence your decision to get \_\_\_\_\_ cancer screening?

What could your spouse, church, other organization, relative or friend do to encourage your use of \_\_\_\_\_ cancer screening tests?

**Black-White Differences in Cancer Prevention Knowledge and Behavior. (Jepson, Kessler, Portnoy, and Gibbs 1991)<sup>15</sup>**

**ITEMS:**

Do you think that changing your diet can play a role in whether or not you get cancer?

Have you ever had a stool blood test?

Are you currently a cigarette smoker?

Do you exercise at least three times each week?

**SOURCE: Factors Contributing to Health Promotion Behaviors among African-American Men. (Million-Underwood, Sanders 1990)<sup>16</sup>**

**ITEMS:**

Do you think that testing for \_\_\_\_\_ cancer should be included as a part of your physical exam?

Do you think that doctors and other health care providers should talk to Black men about their cancer risk?

Are you aware of the screening guidelines for \_\_\_\_\_ cancer?

**SOURCE: Behavioral Interventions to Increase Adherence in Colorectal Cancer Screening. (Myers, Ross, Wolf, Balshem, Jepson, and Millner 1991)<sup>17</sup>**

**ITEMS:**

If your doctor verbally recommended that you receive colorectal cancer screening, would this influence you to get the screening?

If you received a letter in the mail from your doctor, suggesting that you get colorectal cancer screening, would this influence you to get the screening?

Which would have the greatest impact on your decision to get screened for colorectal cancer-doctor recommendation (verbal), doctor recommendation (written), community leader recommendation-video or family member/friend recommendation?

Can you describe the kinds of tests that are done to check for colon – rectal cancer? (Ex: FOBT; Flex-sig)

What do you think are the benefits of colorectal cancer screening?

What are some of the drawbacks of this type of screening?

Would you get screened for colorectal cancer even if you hadn't been experiencing any symptoms of this disease?

What are some of the early warning sign of colorectal cancer?

What would be some of the barriers that would keep you from getting barrier that would keep you from getting screened for colorectal cancer? (Ex: cost, discomfort, time, not necessary )

**SOURCE: Factors Associated with Intention to Undergo Annual Prostate Cancer Screening among African American Men in Philadelphia. (Myers ,Wolf, McKee, McGrory, Burgh, Nelson, and Nelson 1996)<sup>18</sup>**

**ITEMS:**

Belief in the salience and coherence of screening

Belief in the efficacy of screening

Belief in the residual value of screening

Concern about screening-related physical discomfort and embarrassment

Screening-related influence of family members and friends

Do you think that the quality of your life would be better if you were tested for prostate cancer than if you were not tested?

Do you know what some of the possible health outcomes of prostate cancer treatment are?

Probe for: Incontinence

Impotence

Urethral Structure

Rectal Injury

Gynecomastion

**SOURCE: Perceptions of Colorectal Cancer In a Socioeconomically Disadvantaged Population. (Price 1993)<sup>19</sup>**

**ITEMS:**

Do you think homosexual men are more likely than other men to get colorectal cancer?

Do you think exercising regularly will affect your chances of getting colon cancer?

What about eating foods high in fat – does this affect risk of getting colon/rectal cancer?

Do you think that colon/rectal cancer runs in families? If so, what does this imply about cancer screening for members of these families?

Do you think poor, older, or Black people are more likely than other people to get colon cancer?

Does having hemorrhoids increase risk of getting colon/rectal cancer?

Do you think that people who have regular check-ups by their doctor need to worry about getting \_\_\_\_\_ cancer?

Which exams are used to detect colon/rectal cancer?

Are you embarrassed by the exams to detect colon/rectal cancer?

What would be some things that would keep you from getting checked for \_\_\_\_\_ cancer even if you wanted to get checked?

**SOURCE: Prostate Cancer: Perceptions of African-American Males. (Price, Colvin, and Smith 1993)<sup>20</sup>**

**ITEMS:**

What are some of the early warning signs of prostate cancer?

Can prostate cancer be prevented?

Have you ever talked to your doctor about having your prostate examined?

Do you think that African American men are at higher risk than other men of developing prostate cancer?

Does age have anything to do with likelihood of getting prostate cancer?

Are straight or gay men more likely to develop prostate cancer?

Compared to other men your age, do you think you are more or less likely to develop prostate cancer?

What are some of the benefits of prostate cancer screening?

What do you think are some of the barriers to prostate cancer screening among Black men? (Probe for fear, shame, cost, time, uncomfortable exam, etc.)

**SOURCE: African-American Males and Prostate Cancer: Assessing Knowledge Levels in the Community. (Smith, DeHaven, Grundig, and Wilson 1997)<sup>21</sup>**

**ITEMS:**

What is \_\_\_\_ cancer?

Do you think people with \_\_\_\_ cancer can live a normal life if they are treated for this disease?

**SOURCE: Knowledge, Beliefs, Attitudes, and Cancer Screening Among Inner-City African-American Women. (Sung, Blumenthal, Coates, and Alema-Mensah 1997)<sup>22</sup>**

**ITEM:** Are there people in your life with whom you discuss cancer?

**SOURCE: Using Focus Group Methodology to Develop Breast Cancer Screening Programs That Recruit African American Women. (Williams, Abbott, and Taylor 1997)<sup>23</sup>**

**ITEMS:**

Do you think that health care facilities are open at convenient times to allow \_\_\_\_ cancer screening?  
Perception and Efficacy:

Do you think that the results of \_\_\_\_ cancer screening are reliable?

Do you think that most people would have transportation to a health care facility if they decided to get screened for \_\_\_\_ cancer?

What are some ways you could learn more about \_\_\_\_ cancer?

(Probe: Brochures, flyers and pamphlets from doctors' offices and in communities; radio ads; billboards; newspapers; church bulletins; and magazine ads)

Do you think that \_\_\_\_ screening advertising that featured well known African American men to get screened for \_\_\_\_ cancer?

What do you think messages designed to encourage Black men to get screened for \_\_\_\_ cancer should say?

What do you think would be the best format for these messages? (Probe for print ads, TV, radio, magazines, etc.)

What role does spirituality play in the decision to get screened for \_\_\_\_ cancer?

*Task 2 (c): Use the results of the literature search to develop focus group questions (months 8-12)*  
*Step Two: Placing the Identified Potential Survey Items Into a Theoretical Framework*

In the Preventive Health Model, four sets of factors are posited to be related to preventive intention and to carrying out this intention by actually engaging in preventive behavior.<sup>5</sup> These factors are background factors, cognitive/psychological representation factors, social support and influence factors, and program factors. Background factors include sociodemographic characteristics, medical history, and past preventive behavior. Cognitive/psychological representation factors include perceived susceptibility to disease, worry about having the disease, interest in knowing diagnostic status, belief in disease prevention and curability, belief in salience and coherence of behavior, belief in efficacy of detection and treatment, belief in self-efficacy related to behavior, and concern about behavior-related discomfort. The social support and influence factor encompasses the support and influence of family members and health care professionals. Finally, program factors include provider actions that facilitate (or inhibit) preventive behavior.<sup>5</sup>

The classification scheme of the Preventive Health Model, used to categorize each potential survey item identified through the literature search, is presented in the following section of the report.

Potential Survey Items that Are Background Factors:

Which of these groups best describe(s) you? (African American or Black, American Indian or Alaskan Native, Asian, Caucasian or White, Pacific Islander, or Other)

Is there another group with which you identify? If so, with which group? (African American or Black, American Indian or Alaskan Native, Asian, Caucasian or White, Pacific Islander, or Other)

Are you of Hispanic origin? (Yes or No)

What is your date of birth?

Are you male or female?

Are you currently a cigarette smoker?

Do you exercise at least three times each week?

Potential Survey Items that Are Cognitive/Psychological Representation Factors:

*Perceived susceptibility to disease* - Is it possible to have cancer without having symptoms of this disease?

Are you aware of the screening guidelines for cancer?

Can you describe the kinds of tests that are done to check for cancer?

Would you get screened for cancer even if you had not been experiencing any symptoms of cancer?

What are some of the early warning signs of cancer?

What is cancer?

Do you know someone who had had cancer?

Do you think that poor people are more likely than other people to get cancer?

What do you think is your risk of developing cancer, compared to that of other men your age?

Do you think that being older affects your chances of getting cancer?

Do you think that cancer runs in families? If so, what does this imply about cancer screening for members of these families?

Do you think that African American people are more likely than other people to get cancer?

*Worry about having the disease* - What are some of your fears related to cancer screening?

Do you know what some of the possible side effects of cancer treatment are?

*Interest in knowing diagnostic status* - Do you think that some people avoid getting screened for cancer because they are afraid to think about cancer?

*Belief in disease prevention and curability* - What do you think are the most important reasons many African Americans choose not to get screened for cancer?

Do you think that the quality of your life would be better if you were tested for prostate cancer than it would be if you were not tested?

Do you think that people who have regular check-ups by their doctor need to worry about getting cancer?

*Belief in salience and coherence of behavior* - Do you think that some people do not get cancer screening because they just never get around to it?

*Belief in efficacy of detection and treatment* - Do you think that the results of cancer screening tests are accurate?

Do you think cancer can be cured if it is found early enough? If so, do you think that once they are cured, people can live a normal life?

What do you think are the benefits of cancer screening? Would these things motivate you to get tested for cancer?

What are some of the drawbacks of cancer screening? Would these things keep you from getting tested for cancer?

*Belief in self-efficacy related to behavior* - What would be some things that would keep you from getting checked for cancer even if you wanted to get checked?

Do you think that most people would have transportation to a health care facility if they decided to get screened for cancer?



Do you think exercising regularly will affect your chances of getting cancer?

What about eating foods high in fat - does this affect your chances of getting cancer?

*Concern about behavior-related discomfort* - Do you think that some men associate certain tests for cancer with being a homosexual (a man who prefers dating men)?

Would embarrassment keep you from getting screened for cancer?

Potential Survey Items that Are Social Support and Influence Factors:

Do you think that:

Being married

Being a church member

Being a neighbor

Being a member of other types of organizations

Being encouraged by relatives and friends

would influence your decision to get cancer screening? In what ways?

Which types of people or organizations would have the greatest influence over your decision to get screened for cancer?

Are there people in your life with whom you discuss cancer?

What do you think would help to motivate African American men to get screened for cancer?

What are some ways you could learn more about cancer?

Brochures/pamphlets

Flyers

Radio ads

Television ads

Newspaper ads

Church bulletins

Magazine ads

Billboards

Potential Survey Items that Are Program Factors:

To what extent do you think that fear and mistrust of the medical establishment keep Black men from getting screened for cancer?

Does the fact that your doctor is a male/female affect your decision to get cancer screening?

Do you think that some people choose not to get screened because they cannot afford treatment if cancer were found?

Has your doctor ever talked to you about having a cancer screening test?

If you have ever had a cancer screening test, did you talk to your doctor before you had the screening test? Did you talk to your doctor after you had the screening test?

What do you think messages designed to encourage African American men to get screened for cancer should say?

Do you have difficulty now in getting regular health care? If so, what are some of the problems you are facing?

Do you think that doctors and other health care providers should talk to African American men about their cancer risk? If so, what do you think these providers should say?

Do you think that testing for cancer should be included as a part of your regular physical exam?

Do you think that health care facilities are open at convenient times to allow cancer screenings?

*Step Three: Developing a smaller subset of actual focus group items derived from the list of potential items identified through the literature search.*

The focus group moderator's guide, including the final list of focus group items, is presented in the following section of the report.

**Focus Group Questions for Cancer  
Screening Survey Development**

**Facilitator: Marvella Ford**

**Assistant: Deanna Hill**

**Recorder: Felecia Collins**

**Tuesday, January 25, 2000**

**6:00 p.m. - 8:00 p.m.**

**I. WARM-UP AND EXPLANATION (10 minutes)**

**A. Introduction**

1. Good evening. My name is Marvella Ford. I work here at Henry Ford Health System. This is Deanna Hill. Deanna also works here at Henry Ford Health System. She will be assisting us this evening. Felecia Collins is the recorder this evening.

2. Thanks for coming.

3. Your presence and participation are important. Your thoughts and opinions that you discuss tonight are valuable in helping us to develop a survey about cancer screening.

**B. Purpose**

1. What we are doing here this evening is called a focus group. It's a discussion to find out your opinions.

2. We are interested in all of your ideas, comments and suggestions.

3. Each of you is very important and all of your comments are welcome.

4. There are no right or wrong answers.

Please speak up -- even if you disagree with someone else here. It's important that we hear what each of you thinks.

### C. Procedure

1. We will be audiotaping and videotaping our discussion. Everything you say is important to us, and we want to make sure we don't miss any comments. Later we'll go through all of your comments and use them to prepare a report on our discussion. However, all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected to your name. Also, if any questions make you uncomfortable, feel free not to answer them.
2. You don't have to wait for me to call on you. However, please speak one at a time, so the tape recorder can pick up everything.
3. We have many topics to discuss so I may change the subject or move ahead. Please stop me if you want to add anything.

### D. Self-Introductions (Ice Breaker)

1. Please tell us your name and your dream vacation.

## FOCUS GROUP QUESTIONS

1. What things come to mind when you hear the word "cancer"?

How do you feel when these things come to mind?

I typically use the words "African American" or "Black" but I was wondering which one you prefer to use? (USE THE WORD THEY PREFER. IF THEY DO NOT HAVE A PREFERENCE, USE "AFRICAN AMERICAN" AND "BLACK" INTERCHANGEABLY.)

2. What do you think are some of the reasons some African American men choose not to get screened for cancer? Cancer screening means getting checked for cancer before you've ever had it.
3. Which types of people or organizations do you think have the greatest influence over the decision of Black men to get screened (or checked) for cancer?

Probe: spouse, neighbor, relatives, friends, church members, pastor, etc.

4. How much of a role do you think religion or spirituality play in the decision of Black men to get screened (or checked) for cancer?
5. What do you think are some of the benefits of cancer screening (or getting checked for cancer before you've ever had it)?

Do you think that these benefits motivate some Black men to get screened (or checked) for cancer?

6. What do you think are some of the drawbacks of cancer screening?

Do you think that these drawbacks keep some Black men from getting screened (or checked) for cancer?

7. What things do you think would motivate Black men to get screened (or checked) for cancer?
8. To what extent do you think that fear and mistrust of the medical system keep Black men from getting screened (or checked) for cancer?
9. Would the cost of cancer treatment if cancer is found keep you from getting screened (or checked) for cancer?
10. How much would embarrassment keep you from getting screened (or checked) for cancer?
11. What are some of your fears about cancer screening?
12. Do you think that people who have regular check-ups by their doctor need to worry about getting cancer?

What makes you say this?

13. Do you have difficulty now in getting regular health care?

If so, what are some of the problems you are facing (Probe: waiting time to get an appointment; transportation problems; cost; time away from work)

14. Do you think that testing for cancer should be included as part of the physical exam done by your doctor?

What makes you feel this way?

15. Do you think that doctors and other health care providers should talk to Black men about their cancer risk?

(If yes, probe: What kinds of things do you think doctors and other health care providers should say to Black men about their cancer risk?)

16. Does your doctor talk to you about your risk of getting cancer?

(If yes, probe: What kinds of things does your doctor talk to you about, in terms of your risk of getting cancer?)

17. What could your doctor do to encourage you to get screened (or checked) for cancer?

(Probe: verbal recommendations and/or letters suggesting screening)

18. Do you think that health care clinics and hospitals are open at convenient times for cancer screening (or getting checked for cancer before you've ever had it)?

(If not, probe: What could be done to make the times more convenient for people to get cancer screening?)

19. Do you think that using t.v., radio, newspaper and magazine ads to encourage Black men to get screened (or checked) for cancer would be effective?

(Probe for reasons why or why not: Let's start with t.v. ads...Now, let's talk about radio ads.)

(Probe: If men think ads would be effective say: What should these ads look or sound like? Who should be in them?)

20. How accurate do you think that the results of cancer screening tests are?

21. How likely do you think it would be for you to have cancer without having any signs or symptoms?

22. Do you know someone who has had cancer?

23. Do you think cancer can be cured if it is found early enough?

What makes you feel this way?

24. Do you think that people who have had cancer can live a normal life?

What makes you feel this way?

25. Do you think that your life would be better if you were screened (or checked) for cancer than it would be if you were not screened (or checked) for cancer?

(Probe: In what ways would your life be better? In what ways would your life not be better?)

26. Do you think that some men associate certain cancer screening tests with homosexuality or with men who prefer to date other men)?

27. How do you think that being older affects your chances of getting cancer?

28. How do you think that being African American affects your chances of getting cancer?

29. What do you think your risk is of getting cancer, compared to other men your age?

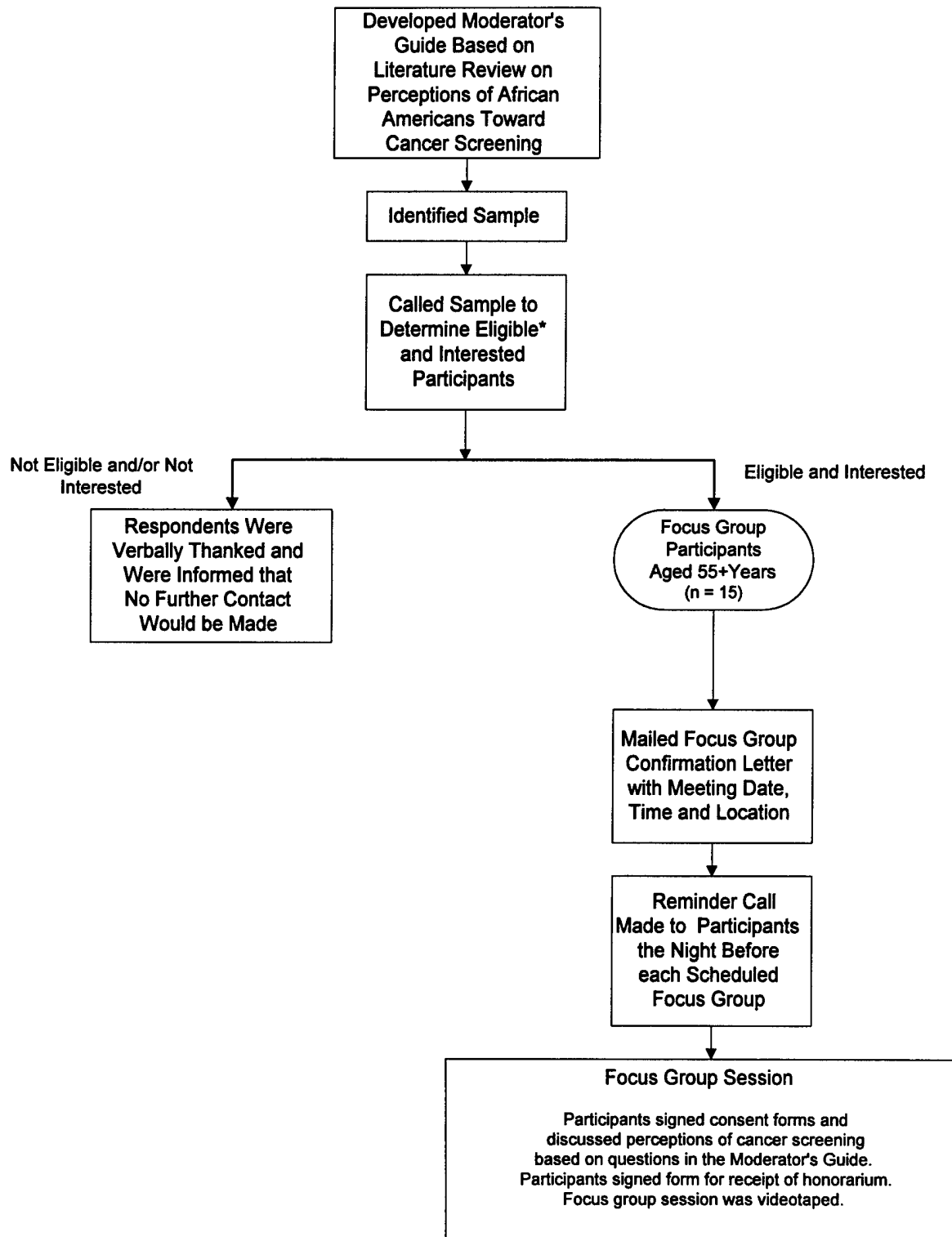
Thank you very much for coming today. Your comments are greatly appreciated. Everything that you have said tonight will help us to prepare a survey to look at perceptions of cancer screening.

Again, thank you very much.

*Task 2 (d): Hold a focus group session to assess participants' perceptions of the developing measurement instrument and to garner ideas for new questions (month 13)*

**Figure 2**

**Methods Used in the Focus Group**



\*confirmed age, race/  
ethnicity, and gender



The study processes involved in identifying focus group participants are depicted in Figure 2. Basically, all African American men who had made at least one visit to Henry Ford Health System in the past year, and who were over the age of 55 years, were selected. Then, the names and birthdates of the men on this listing were compared with the names and birthdates of the African American men in the PLCO Trial. Men who were part of the PLCO Trial were excluded from participating in the focus group.

A random sample of the remaining names was taken, and given to trained telephone interviewers, who called the men on the list to invite them to participate in the focus group. During the telephone call, the interviewers confirmed the age and race of the men, and confirmed that they were not taking part in the PLCO Trial. If the men were not interested or able to participate in the focus group, they were verbally thanked for their time in taking the invitational telephone call. If the men were interested and able to come to the focus group, they were thanked. The interviewer continued calling the men until 15 men indicated that they would like to participate in the focus group. These men were then sent a reminder letter confirming the date, time, and location of the focus group. The night before the focus group was scheduled to take place, the 15 men received a reminder telephone call. At the conclusion of the focus group, the men signed a receipt and received \$25 in cash as an honorarium. Ten men participated in the focus group.

#### **Focus Group One: Results**

Ten men participated in the focus group. These men ranged in age from 55-87 years, with a mean age of 73.4. The age of the men was fairly evenly distributed by decade.

Content analysis of the focus group transcripts was conducted. Following the approach used by Vuckovic, Ritenbaugh, Taren, & Tober,<sup>24</sup> transcripts were coded to index categories of responses. The transcripts were independently coded by the investigators and were checked for accuracy against notes taken during the focus groups.<sup>25</sup> The coding process provided a systematic approach to identifying themes in the data.<sup>26</sup> Statements identified from the data were open coded and grouped into conceptual categories, themes or axial codes by consensus among the investigators.<sup>26-28</sup> Themes related to survey questions that were common across both focus groups were identified, as well as themes unique to a particular focus group. The focus group data analysis revealed the following themes. Comments related to each them reflect statements made by unique individuals. Multiple comments by the same individuals are not included as separate statements.

Themes emerging from Focus Group 1 are shown in the Table 11. This table shows that these themes include motivation to participate in developing the survey and experiencing symptoms as motivation for previous cancer screening.

Themes shown in Table 11 also include the social support and influence factors of the importance of transferring health information intergenerationally in families and encouragement by others as motivation for cancer screening.

Cognitive/psychological factors shown in Table 11 include the perceived benefits of cancer screening, belief in the efficacy of early detection as motivation for cancer screening, fear as a barrier to cancer screening, lack of belief in provider efficacy, belief in provider efficacy, lack of belief in the accuracy of cancer screening tests, belief in the accuracy of cancer screening tests, knowledge/awareness of actions screening produces abnormal results, seeking knowledge as motivation for previous cancer screening, lack of knowledge regarding cancer screening tests, lack of

knowledge regarding cancer, knowledge regarding cancer, knowledge of diet as a cancer risk factor, lack of association between cancer screening and homosexuality, associating cancer with age, associating cancer with stress, discomfort of procedures as a reason not to get screened and knowledge of the use of PSA tests for cancer surveillance.

Programmatic/systemic factors shown in Table 11 include the role of health care providers, the role of health care settings, the role of computerized medical records, the role of health insurance coverage and the need to work to earn money, which may preclude having time available to participate in cancer screening activities.

Table 11. Themes Emerging from Focus Group 1

Theme	Comments Related to the Theme
Motivation to participate in developing the survey	<ul style="list-style-type: none"> <li>□ “Well, I think this (focus group) is one of the best things that could ever happen. Because I had been knowing about this (issue of cancer in African American men) for years. I did twenty-two years at ____ Hospital as a physical therapist. And I have sons and grandsons, and I want to be able to help them”</li> <li>□ “Well, I have had the colon cancer test, and I have had the prostate cancer test, so everything was good in that area so now I ... still want to know more. I even have books at home about it (cancer), and I went to the health food store yesterday and they gave me a couple of magazines and I went through them and one of them was talking about cancer, too. And it is not always women who have cancer”</li> </ul>

Theme	Comments Related to the Theme
Experiencing Symptoms as Motivation for Previous Cancer Screening	<ul style="list-style-type: none"> <li>□ “Well what caused that is I was having bleeding in my rectum. And that was one of the reasons why I was bleeding in my rectum”</li> <li>□ “When they went into my rectum and screened my lower intestines, they couldn’t find out what the cause of the bleeding was so they just told me to leave the popcorn and peanuts and seed and whatever leave them alone because I had gastritis... So then they went through that and then the next time I had to go in and have a colon test and I was kind of upset about that one. And I went into that one and they did the same thing but instead of going into the lower part they went into the upper part. So they checked the upper part and they showed me the pictures and it was all right”</li> <li>□ “This April I will be 88 and years ago after I left _____ Hospital, I had this urging to go to the bathroom, I did not know what was going on and the last time the urine would not flow. And when it did a clump of blood came out. Then I went to _____ Hospital, and after that I was alright”</li> <li>□ “When speaking in terms of problems with urination and actually, as many of us get older, we have these particular problems but many times it is simply just an enlargement so far as the prostate. What happens is that you are squeezing and you can’t get it out and it really is a problem. And I went in for this particular condition but you don’t know whether or not it is cancer or whether or not it’s just an enlargement. So you need to get that examined. For me, that was the case and for me, it was just an enlargement. So the route we went is Roto Rooter. They put you to sleep, and it’s all dead down there and you don’t feel anything. And after, then it’s beautiful to be able to relieve yourself and you can”</li> <li>□ “I cannot imagine myself just walking into a doctor’s office and saying, ‘I don’t have any symptoms but would you check me for something?’ I just couldn’t imagine myself doing that”</li> </ul>

Theme	Comments Related to the Theme
Experiencing Symptoms as Motivation for Previous Cancer Screening (cont'd)	<p>□ “My experience was I had always gone through the digital thing, and my doctor knew I had hemorrhoids, and do the smear thing. It (the test result) came in and it had a little bit of blood on the smear and he (the doctor) said, ‘I know you’ve got hemorrhoids and that could be from that, but I want you to take this scope thing just to be sure, you know because it may be some cancer.’ And that is all he had to say, you know that it could be, and you know it was no question I was going in to get that test”</p> <p>Likelihood of following doctor’s suggestions to get screened:</p> <p>□ “You know, it depends on why he is saying that. Is he saying that he suspects that you have cancer, it’s a possible cause, or is he saying it because maybe it’s his policy to tell all his patients to get screened for cancer? (If the latter is true) I would do it, I might or might not... But if he told me that my PSA was elevated and I better go see, I would go under those circumstances... If he pointed out to me that your white blood cells count is ten times abnormal, then go see if you got leukemia. Then I would go get a test”</p> <p>□ “If I have symptoms, if he (doctor) says do this (get screened for cancer) because of something (symptoms), yes (I would get screened); if he says I don’t have any specific reason (for suggesting screening) then I might or might not (get screened)”</p>

Theme	Comments Related to the Theme
Social Support and Influence Factor: Importance of Transferring Health Information Intergenerationally	<ul style="list-style-type: none"> <li>□ "Awareness, they got to have elder people more educated (about cancer screening) and let them take care of the young ones (getting screened for cancer)"</li> <li>□ "If you can get it through the older peoples minds, to be tested, (such as) for diabetes then maybe they would put it down to the little children and take them and have them tested... It (raising awareness through churches) works; it works to get the message out"</li> <li>□ "You see, I had three heart attacks. My son came to me when he had to go in and have one of these tests (for his heart), and he asked me what did I have to go through for this test. And I sat down and I explained it to him how this test comes about. So when he went into the hospital and when they wheeled him into the operating room, I was there, and I told him do exactly what they tell you and you will come out all right. And he did and he came out all right"</li> <li>□ (Information about cancer symptoms described at church): "Right, because if they (the family) are looking at the pew and somebody just got up there and said, in other words describe if these things (cancer symptoms) are happening to you, the family is looking, in other words, that brings the family in and its going to touch something in that house"</li> <li>□ Because they will discuss it at the dinner table"</li> <li>□ "When we were talking about the family we were talking about us talking with our children. I was thinking just the opposite. If one of my daughters tells me, 'Dad, you are looking kind of peaked, you need to go in and get checked', you know, that would encourage you much more than if my mother said, 'Have you been checked lately?'. And I experience with my mother this last year, she was really sick and I was telling her, 'You need to go to the doctor', and she didn't want to listen to me, but as soon as my daughter said, 'Granny, you need to get to the doctor', she (mother) was putting on her coat to go, because she knew that she needed to go. So maybe your public service announcements would say, 'Have you looked at your parent?'. We've got an aging society now. 'Have you looked at your parents, are they getting tired'?"</li> </ul>

Theme	Comments Related to the Theme
Social Support and Influence Factor: Encouragement by Others as Motivation for Cancer Screening	<ul style="list-style-type: none"> <li data-bbox="602 216 1386 426">□ "So what made me do these things (getting screened) is that I have a member in my parish he has cancer and he told me 'Whatever you do, you go in and have them check you out for rectal cancer and your colon'. So I said whenever I go see my doctor I will put it (cancer screening) on her mind"</li> <li data-bbox="602 430 1386 573">□ "I am in the Disabled American Veterans office and some of those guys we have to drag them down there (to get screened) and threaten them, you know they don't want to go (to get screened)"</li> <li data-bbox="602 577 1386 804">□ "We get warnings all over TV (regarding the need for cancer screening)... and pretty soon you don't pay it any attention. I think in order to get some reaction you have got to be able to relate to that person and their own frame of reference, you know in order to get their attention, not just some well know person on TV"</li> <li data-bbox="602 825 1386 1003">□ "How about (raising) awareness through the churches?... That information would be important...(knowing whether) there is a greater possibility of you getting cancer because you are black...if you had a black man (saying this)"</li> <li data-bbox="602 1008 1386 1444">□ "...there is an effective way and that is the publicity. When people began to die ... with lung cancer, look at what they started doing to the cigarette companies, to the tobacco companies. They've got every conceivable kind of advertisement about what smoking too much will do, they've even got it on the pack. In Canada they've got pictures of cancerous lungs. They are going to put that on a cigarette pack ... because smoking causes cancer... It (negative publicity) is effective; look at the number of people who stopped smoking... Think about (how if)every time you bought a pack of cigarettes, on the outside of the pack is a picture of a diseased lung"</li> <li data-bbox="602 1449 1386 1652">□ "I think it is the type of message you get out that would affect me. If there is a message that just says go and get checked every year, that probably would not affect me, but if the message was out there, these are the symptoms, there is a symptom that I can associate with, then I would go and ask for that test"</li> </ul>

Theme	Comments Related to the Theme
Social Support and Influence Factor: Encouragement by Others as Motivation for Cancer Screening (cont'd)	<ul style="list-style-type: none"> <li>□ "Just like he (another participant) was saying before, somebody who we know has had the disease, come back just like Claude Young (the former Mayor's cousin, who is a physician), we all know him, (we would) all listen to him and say, 'Hey, we'd better check this out'"</li> <li>□ "Personally I think it (cancer screening) is a personal discussion and you have to talk to them one on one... I think that the idea was brought up before that the TV is a very good way to do that"</li> </ul> <p>Disagreement:</p> <ul style="list-style-type: none"> <li>□ "I know, and everybody in this room knows the stats, that black people get cancer, prostate cancer, so what more can you do, because we all know that and you are right back to square one"</li> <li>□ "Putting someone up there to say, 'Black men or African American men have cancer 50% more (than Caucasian men)' is not going to do anything for me. But if he (someone) gets up there and says, 'I have to get up and urinate three times a night, you need to get this checked out, or do you have a burning sensation, do you have some blood in your stools, you better go get checked out' (would motivate him to get screened)"</li> <li>□ "You don't have to have somebody out there that is well known to do that (describe cancer symptoms)"</li> <li>□ "...it (describing cancer symptoms) would bring about a better awareness (of the need for cancer screening)"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Perceived Benefits of Cancer Screening	<ul style="list-style-type: none"> <li>□ "It (screening) puts your mind at ease. The relief"</li> <li>□ "The piece of mind"</li> <li>□ "The quality of life"</li> <li>□ "Longer life but for that it is just the pleasure of being able to urinate. Some of these things you take for granted until you can't"</li> </ul>
Cognitive/Psychological Factor: Belief in the Efficacy of Early Detection as Motivation for Cancer Screening	<ul style="list-style-type: none"> <li>□ "I have seen people who have waited too long (to get screened for cancer) and really suffered"</li> <li>□ "In relationship to people not coming in or being afraid to come in for a particular test because the fact that they might have cancer, again we are talking in terms of if they are well aware of the fact that the sooner they come when they have cancer, the sooner it is taken care of, the sooner they might get well and the longer it takes for them to get in, they may die from it (cancer). Again, if they have that kind of information why should they be afraid to come in? They should be afraid not to come in (to get screened)"</li> <li>□ "I don't want to get to the symptoms; I want to know before I get the symptoms"</li> <li>□ "You know, anybody that has had a family members suffer, die from cancer I believe will be very reluctant to go to a doctor and say 'I want to be tested for cancer'...But then there are an awful lot of people who have seen people suffer like I saw my father suffer, who are very reluctant to find out that they have such a disease as this. You know they have other diseases and won't go to the hospital or doctor... It didn't make me feel reluctant (to get screened), but I became more afraid of whatever happened to me it must be cancer... people who have seen suffering like that, they are very reluctant because they don't want to suffer"</li> <li>□ "Now I have just the opposite opinion about being afraid to go (to get screened for cancer). I worked with a guy maybe twenty years who thought maybe he had a peanut caught in his throat and turned out to be cancer, so with me now every time something happens or I feel something is not there I want to get it checked out just the opposite and just to make sure that I don't have or I can start my treatment early so I guess I don't understand why someone would be afraid to go in a get checked out if they got it they got it so better to find out and get some treatment than to just suffer with it"</li> <li>□ "I am definitely afraid of that sigmoid(oscopy), I tell you the truth. I have already avoided it"</li> </ul>



Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Belief in the Efficacy of Early Detection as Motivation for Cancer Screening (cont'd)	<ul style="list-style-type: none"> <li>□ "A lot of people are talking about being afraid of that scope for colon cancer"</li> <li>□ "I don't have a problem with blood tests, and x-rays...you know, that stuff doesn't bother me but the sigmoid(oscopy), that's terrifying. What I am trying to say is if somebody, some inventor, could come up with something that could make that (colon cancer screening) easier, or they could put you to sleep or something, that would be much better"</li> <li>□ "I was apprehensive about that (sigmoidoscopy), but I asked that doctor this one question. I said, 'How long is it?' He told me so many centimeters, I said no, no in feet, he said 2 ½ feet. He said you would hardly feel it"</li> </ul>
Cognitive/Psychological Factor: Lack of Belief in Provider Efficacy	<ul style="list-style-type: none"> <li>□ "Now one of the things that I found out is that a lot of the doctors do not, cannot diagnosis cancer and we go to these people and they will tell you that maybe there is something else wrong, and you will be treated for something when you really have cancer"</li> <li>□ "I had an appointment to have one (a colonoscopy) and the first one I had, I had a little abrasion that came from the way the instrument was used, so I had a little sore spot, well it got well, but I have a tendency to think that when you are taking these tests, is the technician whoever is doing them, are they doing their job, correctly and as far as first aid, are they using good hygiene? This is the only thing I seem to worry about"</li> <li>□ "Now the medical journal stated that ham wasn't good for the African American person. Then they turned around from two weeks to a month later and they said there was nothing wrong with the African American eating ham, as long as it is lean. Now they turned around one time before and said salt was against the African male people, then they turned around and they changed it and said you can use salt, but a ¼ of a teaspoon. You see so when they go through those type of changes with you, they make you think, 'Why I am over here in the rehab. center going through these various lectures?' I told one of the physicians over there 'Now look, now you people go by what the American Journal says and then you take and translate it over to us what you want us to know'. Well I'm going to tell you something... I can eat me a big spoon of whatever there is to eat and let that do me"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Lack of Belief in Provider Efficacy (cont'd)	<ul style="list-style-type: none"> <li>□ "He (a patient) will go in and maybe the doctor will see and maybe he won't even catch it (cancer) the first time"</li> <li>□ "I'm sure that everybody here has had a doctor who will tell them what they want them to know and no more"</li> </ul>
Cognitive/Psychological Factor: Belief in Provider Efficacy	<ul style="list-style-type: none"> <li>□ "That is the only reason I got it (received a PSA test due to doctor's recommendation for the test)"</li> <li>□ "My doctor just suggested that I get it (a PSA test). She said it was something new"</li> </ul> <p>Likelihood of following doctor's suggestions to get screened:</p> <ul style="list-style-type: none"> <li>□ "All the way"</li> <li>□ "Would I follow-up? I certainly would"</li> <li>□ "I've been to my doctor and my doctor has said, 'I think it is time for you to do a test', and if he says it's time for me to do the test, I am going to do the test. But if he said, 'You don't have any symptoms or anything but I just think that it's time that you do it (get screened), I'm going to take the time and do that test, because he has some reason for saying this. And if I didn't trust him I would find another doctor... Oh, yeah (person indicated that they would take time off work to follow doctor's suggestion to get screened)"</li> <li>□ Well, I tell you my physician, she's on the ball every time I go to her. In fact she is a member of my church. So if she doesn't see me on Sunday's she'll see me on Monday's. So I don't have any qualms with her... she makes sure that I have all of my tests. I am under this new medication she put me under and this new medication has a diet to it... she keeps me pretty well up to date with all of my tests"</li> </ul>
Cognitive/Psychological Factor: Lack of Belief in the Accuracy of Cancer Screening Tests	<ul style="list-style-type: none"> <li>□ "I was wondering what good it would even do to test for cancer. Some cancers you can test for and some you can't. Some are only evident when you have symptoms... You know there is a problem with prostate cancer, because now they are saying that even if find prostate cancer, it doesn't make a difference, people who are treated for it and people who are not treated for it die at the same rate"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Belief in the Accuracy of Cancer Screening Tests	<ul style="list-style-type: none"> <li>□ "They've got to follow-up to see how accurate it (the test result) is"</li> <li>□ "No (the tests are not pretty accurate)"</li> <li>□ "They only give you an indication and then you have to go in and take a biopsy</li> <li>□ "My grandson, they (doctors) said that he was cured, ... and then they had to call him back to take some more tests. He had the chemotherapy, they gave him his chemotherapy again. He told the nurse, 'Is this the last one, because I've got to go to work, I've got to eat'...my question is when they give you this chemo, I mean it's not perfected yet, see, to the extent where they can say you are cured, that is what I am talking about... You see, we are at the mercy of the doctors and the technicians. When they give you tests ,whatever procedure it is, and the results are read back to us, we listen (but) how can we tell whether it is accurate or not accurate, you know until we get too sick or in other words we would have to have something physical or something happen to us that is not right for us to say that that test wasn't too good"</li> </ul>
Cognitive/Psychological Factor: Knowledge/ Awareness of Actions if Screening Produces Abnormal Results	<ul style="list-style-type: none"> <li>□ "Now if you check and find out and actually find out that symptoms do actually arise, what do you do, go see your physician?"</li> </ul>
Cognitive/Psychological Factor: Seeking Knowledge as Motivation for Previous Cancer Screening	<ul style="list-style-type: none"> <li>□ "I have to make an observation there, because you got to face it, you never know what it is going to be like unless you go someplace and get it checked out"</li> </ul>
Cognitive/Psychological Factor: Lack of Knowledge Regarding Cancer Screening Tests	<ul style="list-style-type: none"> <li>□ "I guess I never associated the DRE test with checking for any kind of cancer there. I thought he was checking for something else. Every time I go for an exam he (my doctor) does that (a DRE), then he suggests doing the PSA even after that, so that is why I thought it was different"</li> <li>□ "Like he said, I had them go up in my rectum when I was young, I was about 22. I had that type of test, but this PSA test, I don't know whether the doctor gave me that, but I get my (physical) examination every year"</li> <li>□ "What other types of test can you use? How would they (doctors) determine lung cancer?"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Lack of Knowledge Regarding Cancer	<ul style="list-style-type: none"> <li>□ "I believe that (TB) was a form of lung cancer in the days before they really identified it. TB was a common cause of death, but actually that (TB) is cancer isn't it?"</li> <li>□ "Tuberculosis is an infection"</li> <li>□ "Yeah, so is cancer"</li> <li>□ "At the beginning of the last century on a basis of one to ten cancer is very low on the list of fatal diseases now I think it is about number 2 not that there are fewer people dying with cancer but I think the medical profession has honed in on some of the others"</li> </ul>
Cognitive/Psychological Factor: Knowledge Regarding Cancer	<ul style="list-style-type: none"> <li>□ "It is, eating away the tissues. I thought that is what cancer does"</li> <li>□ "Cancer is a growth, an abnormal growth. An abnormal growth of cells"</li> <li>□ "Yeah, it destroys the healthy cells"</li> <li>□ "We are generally here all past the year, the stage when prostate starts, and after 40 years of age, that's when you'd better start to look at it. Now if you know what the prostate does and what it is, it helps fertilize the egg for reproduction. And I guess everybody knows how it is situated in the body, and what happens when it (cancer) first begins to squeeze the tube that brings the urine from the bladder, and the urine can't get through there, and after 40 years of age, some people can pass it over and skip it and some don't but usually that's the time when you should be concerned (about prostate cancer)"</li> </ul>
Cognitive/Psychological Factor: Knowledge of Diet as a Cancer Risk Factor	<ul style="list-style-type: none"> <li>□ "Our diet for African American men is one of the worst things there is. We say the same old thing, 'I know I'm not going to have it, but I just want a little piece'. A little piece of that ham, coconut cake"</li> </ul>
Cognitive/Psychological Factor: Lack of Association Between Cancer Screening and Homosexuality	<ul style="list-style-type: none"> <li>□ "When I was in the service they gave you that test; I never thought of that (homosexuality), I just hated the idea of somebody doing it"</li> <li>□ "That's what I wanted to address...I think 90% of that is psychological"</li> <li>□ "It is the technician that does the work. Being sexually orientated in the wrong way, it is hard for you to do anything about that. That's up to the employer. See I am coming in to a physician to be waited on for some ailment, I not going to put the technician under observation. I am taking it that I am in good hands"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Lack of Association Between Cancer Screening and Homosexuality (cont'd)	<ul style="list-style-type: none"> <li>□ "It's hard for you to observe"</li> <li>□ "You can observe, they've got a TV monitor up there. I saw it when they were going up in me. And what can you do about it? You can't do a thing about it but sit there and look (as the procedure is being done)"</li> </ul>
Cognitive/Psychological Factor: Associating Cancer with Age	<ul style="list-style-type: none"> <li>□ "I think that a lot of the organs can't fight off like they used too (as they age). A lot of medicine we can't take because your doctor says it is interfering with another medicine you are taking... this medicine here is supposed to help take care of the cancerous cells, but you can't take it because like me you are taking your diabetic medicine"</li> </ul>
Cognitive/Psychological Factor: Associating Cancer with Stress	<ul style="list-style-type: none"> <li>□ "See I'm not a doctor but I could be a doctor because every time a black man would come into my office, you know what I would tell him? What every doctor tells a black man, first of all we got a little tiny bit of sugar, you got high blood pressure, and we see a little something there. But we're in the United States and we are going to have that stress factor. You were so glad years ago when you got one of the worst jobs wherever you went, you were glad to get it, you got the job... you talk about stress, that is one of the symptoms, that brings about prostate cancer"</li> <li>□ "He's right about the amount of stress. That could be one of the causes (of cancer), it (stress) is built up over the generations...I think a lot of us men and I am sure women know that during the time as far as affirmative action on the job I know I came up and I knew my job well, you get in there but you are always under a microscope. You knew somebody was always standing near you. So with that type of stress you know you get off work and you go home and you have family life but sometimes some of that gets to you, you know. It's an everyday thing and I worked 30 years before I retired, you know what I mean. In 30 years it was day to day stress, you know somebody was out to get you, or trying to get to you and I know it, because I knew my job 4 times better or five times better than my co-workers did. But the point is there was always somebody up there trying to put you down. So I'm just trying to tell you about the stress factor...I'm saying it was real... I don't think anybody in the room can sit here and say that they didn't have day to day stress, unless you were working for yourself, then the stress level was worse, but it was a different kind of stress"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Associating Cancer with Stress (cont'd)	<ul style="list-style-type: none"> <li>□ "I had a black out. My blood pressure went up so high and I had a black out and everything turned black and the next day I went up there and signed for retirement"</li> <li>□ "Now we talking about the playing field, you take economics come in there too. Just like he mentioned the post office, I started at the post office \$1.31/hr and I couldn't take care of my family. I mean a two week check come, I know what I had coming. And I got my check and it was \$232 that was a two-week check. Twelve hours a day, and I just felt like crying... I had six babies at home, I had to go to ____ and get me a better job"</li> </ul>
Cognitive/Psychological Factor: Discomfort of Procedures as Reason Not to Get Screened	<ul style="list-style-type: none"> <li>□ "The uncomfortableness of the procedure (kept him from getting screened"</li> <li>□ "Yeah, just like he said, knowing that someone is going to be going up your rectum, just the thought of it I guess. Unless you just have to go in there, you are not going to go. So, sometimes you wait too late which is ultimately what is going to have to happen"</li> </ul>
Cognitive/Psychological Factor: Knowledge of the Use of PSA Tests for Cancer Surveillance	<ul style="list-style-type: none"> <li>□ "The PSA is just a follow-up, you know when they do that rectal test it is what ever his opinion is but to actually tell you if it is cancer that is really, not really dormant we say the PSA test lets you know what level it is, that is the real test. Once you get prostate cancer, you get a procedure or something the PSA test you go in for every six months or whatever the doctor say to see if it is maintaining the same level and that is how they monitor a person who has prostate cancer"</li> </ul>

Theme	Comments Related to the Theme
Programmatic/Systemic Factor Related to Cancer Screening: Role of Health Care Providers	<ul style="list-style-type: none"> <li data-bbox="602 222 1386 359">□ "When you are going through the procedure, you can analyze these techniques and you know when the man does a good job. You know he does a good job when he gives you awareness or this or that, it is a job well done"</li> <li data-bbox="602 369 1386 537">□ "I think in all these cases you are talking in terms of the person comes in and it is adequately explained what is going to happen and how it is going to happen and what procedure and precautions have been taken previously for that particular procedure"</li> <li data-bbox="602 548 1386 758">□ "You said your friend (who died of colon cancer) came in (to the health system) for a physical every year. Can you explain why when the person came in for a physical that the people that gave them that physical didn't include tests for colon or prostate cancer? Some of these things you can just discover by giving them a test"</li> <li data-bbox="602 768 1386 905">□ "When you are going through the procedure, you can analyze these techniques and you know when the man does a good job. You know he does a good job when he gives you awareness or this or that, it is a job well done"</li> <li data-bbox="602 915 1386 1083">□ "I think in all these cases you are talking in terms of the person comes in and it is adequately explained what is going to happen and how it is going to happen and what procedure and precautions have been taken previously for that particular procedure"</li> <li data-bbox="602 1094 1386 1304">□ "You said your friend (who died of colon cancer) came in (to the health system) for a physical every year. Can you explain why when the person came in for a physical that the people that gave them that physical didn't include tests for colon or prostate cancer? Some of these things you can just discover by giving them a test"</li> <li data-bbox="602 1314 1386 1482">□ "And when I was looking at this purpose of this study, it is really to see if you have a procedure or a standard way that people should be going in for physical exams, and when they go in for a physical exam do they (health care providers) test for the things"</li> <li data-bbox="602 1493 1386 1797">□ "...now when you said that your doctor should do it (screen for cancer periodically), ... now if you have a care person, you have your medical record, now your physician, each time you go see your physician, your physician goes through these records supposedly, now sometimes you have to make sure that they go through these records. But if they go through these records and you have these various test, they know when you are due for your next one"</li> </ul>

Theme	Comments Related to the Theme
Programmatic/Systemic Factor Related to Cancer Screening: Role of Health Care Providers (cont'd)	<ul style="list-style-type: none"> <li>□ "(But) you may be going to different doctors. When you go to one doctor they have one record and you go to another doctor, he's got a record, and they don't have access to the previous records"</li> <li>□ But you go to the doctor, I don't know what the experience is, but I have seen time and time again, doctors today keep fighting the HMO's. You go to doctor and he will give you ten minutes, he does not have time to give you the examination or screening examination. I go to doctors all the time because I am not well. I don't have a heck of a lot of time; I was going down to Cleveland Clinic because that was the only place I could go where they gave me enough time to see what was wrong with me"</li> <li>□ "(A) periodic check-up (should take place) every six months for people that are 65 or older. In other words, you go in and schedule yourself for a physical and that physical that you are going to be scheduled for is going to target certain things in that age group, and that is what you go in for and the doctor says, 'Ok, then, you are fine. Come back and see me in six months or so'...That's what needs to happen. If they establish a profile in the department they have a bunch of people that have been trained to do this, that is when it comes out. And if that patient ignores that check-up then no better for them"</li> <li>□ "I know at my doctor's they make you fill out this postcard in your own handwriting so that when it is close to time for your appointment, you get this postcard in the mail. It makes them and you aware of the fact that you have an appointment"</li> <li>□ "...if you go to a doctor or a hospital he (the doctor) is not going to initially test you for whatever and see if you have cancer...(provider never suggested that he get checked for cancer)... No, not cancer specifically, but I wanted it after I saw what happened to my father. He was the first to die of cancer. And I went for it specifically"</li> </ul>
Programmatic/Systemic Factor Related to Cancer Screening: Role of the Health Care Setting	<ul style="list-style-type: none"> <li>□ "And if you talk in terms of how can the health community help whether instead of just coming into the hospital just sitting there waiting, rather than watching your sitcoms on television, why not have some educational information there for them (patients who are waiting to see the doctor)"</li> </ul>



Theme	Comments Related to the Theme
Programmatic/Systemic Factor Related to Cancer Screening: Role of Computerized Medical Records	<ul style="list-style-type: none"> <li data-bbox="613 218 1395 1052"> <input type="checkbox"/> "I believe that there should be a department or specialist set-up to review medical records as a form of screening to recommend (patients for screening), like a big hospital like ____ Hospital, they should have someone to review medical records and you know there is a certain profile that you could pull out and you know someone like you (moderator), can study it... I am talking about a special department...It's just that the medical records document everything and people, say our age, when they go in for, some way to trigger someone to screen it, to really go down through this and say this person has never been tested for colon cancer, prostate cancer, but all the symptoms of all these other reasons they have been going to see the doctor over the years is right there in your medical records. So they will evaluate, personally evaluate this (each patient's need for cancer screening). It could be a doctor or medical research, but the point is not to wait for that person to get half dead to come into the hospital (due to symptoms related to cancer)... So they (the patient could then) come in and get a biopsy as opposed to that person, having problems going to the bathroom or something, (because) there is a blockage or something" </li> <li data-bbox="613 1058 1395 1339"> <input type="checkbox"/> "When I go in they will check me; I kind of wish they would send me like reminders of something to do, which they do not do...but what if I am not being treated for anything, and that is why I don't get there every year, because I don't think about it every year. Years have gone by before I think about it (getting screened for cancer) and then it is another 6 months before I make the appointment (to get screened)" </li> <li data-bbox="613 1346 1395 1413"> <input type="checkbox"/> "The reminders are usually when you are being treated (rather than screened), and you do great" </li> <li data-bbox="613 1419 1395 1524"> <input type="checkbox"/> "Like dentists do that; they find out you have good dental insurance and they make sure that you get a notice (for a return visit). Man, those dentists are right on the kicker" </li> <li data-bbox="613 1530 1395 1598"> <input type="checkbox"/> "It seems like that could be computerized, with just your name and age" </li> <li data-bbox="613 1604 1395 1673"> <input type="checkbox"/> "You should get a notice from your doctor and they will send you a reminder" </li> </ul>

Theme	Comments Related to the Theme
Programmatic/Systemic Factor Related to Cancer Screening: Health Insurance Coverage	<ul style="list-style-type: none"> <li>□ When you mean the time frame, every three years to get your colon, what controls that for it to be every three years, the doctor or your insurance coverage?"</li> <li>□ "Yes. I had that (sigmoidoscopy) done last year, so I have two more years to go before I go through it again"</li> <li>□ "If they got insurance and everything, the only thing that would keep them from doing it (getting screened for cancer) is that they got to dig in their pocket and pay that doctor a lot of money, but most of us got insurance"</li> <li>□ "If you take care of that car your transmission is not going to go bad. The motor is not going to go bad except I got to take the time to do that and I have got to do the same thing with my body. Except it is a lot cheaper to go in and get the (screening) test done than to wait until something really serious (is found)"</li> <li>□ "If you belong to an HMO, they (providers) are supposed to maintain health and the doctors are constantly dreading that"</li> </ul>
Programmatic/Systemic Factor Related to Cancer Screening: Need to Work to Earn Money Precludes Time Available for Cancer Screening	<ul style="list-style-type: none"> <li>□ "I have avoided that (a chest x-ray), too. Because sometime the overtime comes up and I needed money (and so did not have time to get screened for cancer)"</li> <li>□ "Is everybody here retired, except me? In other words, there is a difference between the retired guys and the guys that work... The difference is that the guys who are retired can go to the hospital every day and the guys who work can't (because they do not have time to go)"</li> <li>□ "It's not a question of trust (of a doctor), it's that I have more of a priority (to work rather than to get screened)"</li> <li>□ I was just saying if she (doctor) said, 'Oh, by the way, I don't think you have anything and I have no reason to tell you this, but you could go get an x-ray for lung cancer', I probably wouldn't (get screened) but if it were part of the annual check-up I wouldn't have a problem with that because I make plans for that"</li> </ul>

*Tasks 2 (e) - (i): (e) Based on the focus group results, revise the measurement instrument. (f) Hold a focus group session to assess participants' perceptions of the revised measurement instrument. (g) Incorporate participants' suggestions into a further refinement of the instrument. (h) Conduct statistical analyses of the pilot study results. (i) Revise and refine the final measurement instrument, based on the pilot study results.*

Methods used in the first focus group were used to identify a sample for the second focus group (Figure 1). In the second focus group, the 11 men ranged in age from 53-81 years, with a mean age of 68.7 years.

The survey items and wording were validated in the focus group. During the focus groups, cognitive/psychological factors of fear and anxiety regarding cancer diagnosis and lack of knowledge about screening tests and screening benefits were stated. Wives were noted as the most important social support and influence persons affecting screening behavior. Having a trusted health care provider and health insurance were cited as programmatic/systemic screening-related factors.

The survey that was evaluated (and is designed to be administered via telephone) and the moderator's guide used in the second focus group are included in the following paragraphs. This guide contains the set of questions used to elicit responses from focus group participants regarding their perceptions of the revised measurement instrument.

### **Survey Evaluated During Focus Group 2**

#### **(Survey Cover Sheet)**

We are interested in your opinions about your health and the health care that you receive. All of the information that you provide will be kept confidential.

In this section of the survey, I will read some statements about your health and the health care that you receive. Please tell me whether you STRONGLY AGREE, AGREE, NEITHER AGREE NOR DISAGREE, DISAGREE, OR STRONGLY DISAGREE with each statement.

11. Please tell us whether you agree or disagree with the following statements:	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
a. My quality of life would be better if I was checked for cancer than it would be if I did not get checked for cancer.	5	4	3	2	1
b. I would get checked for cancer even if I had not been experiencing any symptoms of cancer.	5	4	3	2	1
c. Some people do not get checked for cancer because they just never get around to it.	5	4	3	2	1
d. Embarrassment would keep me from getting checked for cancer.	5	4	3	2	1
e. Some people avoid getting checked for cancer because they are afraid to think about cancer.	5	4	3	2	1
f. The results of cancer screening tests are accurate.	5	4	3	2	1
g. Some men associate certain tests to check for cancer with being a homosexual (a man who prefers dating men).	5	4	3	2	1
h. Most people would have transportation to a health care clinic if they decided to get checked for cancer.	5	4	3	2	1
i. People who have regular check-ups by a doctor should not worry about getting cancer.	5	4	3	2	1
j. Exercising regularly affects your chances of developing cancer.	5	4	3	2	1
k. Being older affects your chance of developing cancer.	5	4	3	2	1
l. Cancer runs in families.	5	4	3	2	1
m. African American people are more likely than other people to get cancer.	5	4	3	2	1
n. Poor people are more likely than other people to get cancer.	5	4	3	2	1
o. I have a reduced risk of getting cancer, compared to other men my age.	5	4	3	2	1
p. I have the same risk of getting cancer, compared to other men my age.	5	4	3	2	1
q. I have a greater risk of getting cancer, compared to other men my age.	5	4	3	2	1

Please tell us whether you agree or disagree with the following statements:	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
r. Eating foods in high in fat (or a high fat diet) affects your chances of getting cancer.	5	4	3	2	1
s. It is possible to have cancer without having symptoms of this disease.	5	4	3	2	1
t. If cancer is found early enough, it can be cured.	5	4	3	2	1
u. I know the possible side effects of cancer treatment.	5	4	3	2	1

Now I will ask you some other questions about your health and the health care you receive. Again, we are interested in your opinions.

2. What words would you use to describe cancer?

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3. Do you know someone who has had cancer?

[1] Yes  
[2] No

4. Have you ever heard of a PSA test?

[1] Yes (Answer q. 5)  
[2] No (Skip to q. 6)

5. How would you describe this test?

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6. Have you ever heard of a chest x-ray?

[1] Yes (Answer q. 7)  
[2] No (Skip to q. 8)

7. How would you describe this test?

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8. Have you ever heard of a flexible sigmoidoscopy?

[1] Yes (Answer q. 9)  
[2] No (Skip to q. 10)

9. How would you describe this test?

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10. What do you think are some of the early warning signs of cancer?

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11. Do you think that people who have had cancer in their family are more likely than other people to get cancer?

[1] Yes  
[2] No

12. Do you think that people who have had cancer in their family should get checked for cancer more often than someone who does not had cancer in their family?

[1] Yes  
[2] No

13. Do you have any fears and/or concerns about prostate cancer screening? (*IWER, please read: cancer screening means getting checked for cancer before a doctor has told you that you have cancer.*)

[1] Yes  
[2] No (Skip to q. 15)

14. Could you please describe some of these fears and/or concerns?

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15. Do you have any fears and/or concerns about lung cancer screening?

[1] Yes  
[2] No (Skip to q. 17)

16. Could you please describe some of these fears and/or concerns?

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17. Do you have any fears and/or concerns about colorectal cancer screening?

[1] Yes  
[2] No (Skip to q. 19)

18. Could you please describe some of these fears and/or concerns?

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19. What do you think are the benefits of prostate cancer screening?

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[1] None (Skip to q. 21)

20. Would these benefits motivate you to get checked for prostate cancer?

[1] Yes  
[2] No

21. What do you think are the benefits of lung cancer screening?

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[1] None (Skip to q. 23)

22. Would these benefits motivate you to get checked for lung cancer?

- [1] Yes
- [2] No

23. What do you think are the benefits of colorectal cancer screening?

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24. Would these benefits motivate you to get checked for colorectal cancer?

- [1] None (Skip to q. 25)
- [1] Yes
- [2] No

25. Do you think that people can be cured of prostate cancer?

- [1] Yes (Answer q. 26)
- [2] No (Skip to q. 27)
- [3] Don't know (Skip to q. 27)

26. Do you think that people who have been cured of prostate cancer can live a normal life?

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27. Do you think that people can be cured of lung cancer?

- [1] Yes (Answer q. 28)
- [2] No (Skip to q. 29)
- [3] Don't know (Skip to q. 29)

28. Do you think that people who have been cured of lung cancer can live a normal life?

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29. Do you think that people can be cured of colorectal cancer?

- [1] Yes (Answer q. 30)
- [2] No (Skip to q. 31)
- [3] Don't know (Skip to q. 31)

30. Do you think that people who have been cured of colorectal cancer can live a normal life?

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In the next section of the survey, I will read some statements about sources of health information. Please tell me whether you STRONGLY AGREE, AGREE, NEITHER AGREE NOR DISAGREE, DISAGREE, OR STRONGLY DISAGREE with each statement.

51. Please tell us whether you agree or disagree with the following statement:	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
I can learn more information about cancer through:	5	4	3	2	1
a. Booklets or pamphlets	5	4	3	2	1
b. Flyers	5	4	3	2	1
c. Radio ads	5	4	3	2	1
d. Television ads	5	4	3	2	1
e. Newspaper ads	5	4	3	2	1
f. Church bulletins	5	4	3	2	1
g. Magazine ads	5	4	3	2	1
h. Billboards	5	4	3	2	1

For the next set of statements, please tell me how much being encouraged by a spouse, a church member, a member of a club or by relatives and friends would influence your decision to get checked for cancer. Let's start with being married. (*Read Statement a.*)

52. Please tell us how the following statement influence your decision to get checked for cancer:	Entirely	All or Most	Somewhat	Not At All
a. To what extent would being encouraged by your spouse influence your decision to get checked for cancer?	4	3	2	1
b. To what extent would being encouraged by your minister influence your decision to get checked for cancer?	4	3	2	1
c. To what extent would being encouraged by members of a club (Masons, fraternity, etc.) influence your decision to get checked for cancer?	4	3	2	1
d. To what extent would being encouraged by relatives and friends influence your decision to get checked for cancer?	4	3	2	1



Now I will ask you some other questions about people in your life who play a role in your decision to get checked for cancer.

33. Which of the following people have influenced your decision to get checked for prostate cancer? (*Circle all that apply*)

- [1] Minister or church members
- [2] Club members (masons, fraternity, etc.)
- [3] Daughter
- [4] Father
- [5] Mother
- [6] Other family member(s)
- [7] Son
- [8] Wife
- [9] No one
- [10] Other, please describe:

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34. Are there people in your life with whom you discuss prostate cancer?

- [1] Yes (Answer q. 35)
- [2] No (Skip to q. 36)

35. What is their relationship to you? (*Circle all that apply*)

- [1] Minister or church members
- [2] Club members (masons, fraternity, etc.)
- [3] Daughter
- [4] Father
- [5] Mother
- [6] Other family member(s)
- [7] Son
- [8] Wife
- [9] No one
- [10] Other, please describe:

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36. What do you think would help to motivate African American men to get checked for prostate cancer?

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37. Which of the following people have influenced your decision to get checked for lung cancer? (*Circle all that apply*)

- [1] Minister or church members
- [2] Club members (masons, fraternity, etc.)
- [3] Daughter
- [4] Father
- [5] Mother
- [6] Other family member(s)
- [7] Son
- [8] Wife
- [9] No one
- [10] Other, please describe:

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38. Are there people in your life with whom you discuss lung cancer?

39. What is their relationship to you?  
(Circle all that apply)

[1] Yes (Answer q. 39)

[2] No (Skip to q. 40)

[1] Minister or church members

[2] Club members (masons, fraternity, etc.)

[3] Daughter

[4] Father

[5] Mother

[6] Other family member(s)

[7] Son

[8] Wife

[9] No one

[10] Other, please describe:

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\_\_\_\_\_

\_\_\_\_\_

40. What do you think would help to motivate African American men to get checked for lung cancer?

41. Which of the following people have influenced your decision to get checked for colorectal cancer? (Circle all that apply)

[1] Minister or church members

[2] Club members (masons, fraternity, etc.)

[3] Daughter

[4] Father

[5] Mother

[6] Other family member(s)

[7] Son

[8] Wife

[9] No one

[10] Other, please describe:

\_\_\_\_\_

\_\_\_\_\_

42. Are there people in your life with whom you discuss colorectal cancer?

43. What is their relationship to you?  
(Circle all that apply)

[1] Yes (Answer q. 43)

[2] No (Skip to q. 44)

[1] Minister or church members

[2] Club members (masons, fraternity, etc.)

[3] Daughter

[4] Father

[5] Mother

[6] Other family member(s)

[7] Son

[8] Wife

[9] No one

[10] Other, please describe:

\_\_\_\_\_

\_\_\_\_\_

44. What do you think would help to motivate African American men to get checked for colorectal cancer?

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The next set of statements are about your health care experiences. Please tell me whether you Strongly Agree, Agree, Neither Agree Nor Disagree, or Strongly Disagree with each statement.

45. Please tell me whether you agree or disagree with the following statements	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
a. Fear and mistrust of the health system keep African Americans from getting checked for cancer.	5	4	3	2	1
b. Embarrassment about the screening process keeps African American men from getting checked for cancer.	5	4	3	2	1
c. Having a doctor influences people's decision to get checked for cancer.	5	4	3	2	1
d. Having health care insurance influences people's decision to get checked for cancer.	5	4	3	2	1
e. People choose not to get checked because they cannot afford treatment if cancer were found.	5	4	3	2	1
f. Checking for cancer should be included as a part of a regular health care exam.	5	4	3	2	1
g. Health care clinics are open at convenient times to allow people to get checked for cancer.	5	4	3	2	1

Now I would like to ask you a few more questions about your experiences with doctors and your access to health care.

46. Has your doctor ever talked to you about getting checked for prostate cancer?

- [1] Yes  
[2] No

47. Have you ever been checked for prostate cancer?

- [1] Yes (Answer q. 48)  
[2] No (Skip to q. 49)

48. Did you talk to a doctor after you were checked for prostate cancer?

- [1] Yes  
[2] No

49. What do you think messages designed to encourage African American men to get checked for prostate cancer should say?

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50. Has your doctor ever talked to you about getting checked for lung cancer?

- [1] Yes
- [2] No

51. Have you ever been checked for lung cancer?

- [1] Yes (Answer q. 52)
- [2] No (Skip to q. 53)

52. Did you talk to a doctor after you were checked for lung cancer?

- [1] Yes
- [2] No

53. What do you think messages designed to encourage African American men to get checked for lung cancer should say?

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54. Has your doctor ever talked to you about getting checked for colorectal cancer?

- [1] Yes
- [2] No

55. Have you ever been checked for colorectal cancer?

- [1] Yes (Answer q. 56)
- [2] No (Skip to q. 57)

56. Did you talk to a doctor after you were checked for colorectal cancer?

- [1] Yes
- [2] No

57. What do you think messages designed to encourage African American men to get checked for colorectal cancer should say?

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58. Do you have trouble now in getting regular health care?

- [1] Yes (Answer q. 59)
- [2] No (Skip to q. 60)

59. What are some of the problems you are facing in getting regular health care?

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60. Do you think that doctors and other health care providers should talk to African American men about their cancer risk?

- [1] Yes
- [2] No (Skip to q. 63)

61. What do you think doctors and other health care providers should say?

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In the last section of this survey, I would like to ask you questions about your general background, work history and smoking history.

63. Which of the following best describes your race?

- [1] African American or Black
  - [2] American Indian or Alaskan Native
  - [3] Asian
  - [4] Caucasian or White
  - [5] Pacific Islander
  - [6] Other, please describe:
- 
- 

64. Is there another racial group with which you identify?

- [1] Yes (Answer q. 65)
- [2] No (Skip to q. 66)

65. Which of the following best describes this other group?

- [1] African American or Black
  - [2] American Indian or Alaskan Native
  - [3] Asian
  - [4] Caucasian or White
  - [5] Pacific Islander
  - [6] Other, please describe:
- 
- 

66. Are you of Hispanic origin?

- [1] Yes
- [2] No

67. What is your date of birth?

\_\_\_\_/\_\_\_\_/\_\_\_\_  
mm/ dd/ yyyy

68. What is your gender?

- [1] Male
- [2] Female

69. What is the highest grade of level of school that you have completed?

- [1] 8<sup>th</sup> grade or less
- [2] Some high school, did not graduate
- [3] High school graduate or GED
- [4] Post high school training, other than college (vocational or technical training)
- [5] Some college or 2-year graduate
- [6] 4-year college graduate
- [7] Postgraduate (more than a 4-year college degree)

70. What is your current marital status?

- [1] Divorced
- [2] Living with a partner
- [3] Married
- [4] Married, but separated
- [5] Never been married
- [6] Widowed

71. Has a doctor ever told you that you have any of the following health conditions?

- A) Coronary Heart Disease/Heart Attack
- B) Cancer
- C) High Blood Pressure (hypertension)
- D) Diabetes
- E) Stroke
- F) Arthritis

- |         |        |
|---------|--------|
| [1] Yes | [2] No |
| [1] Yes | [2] No |
| [1] Yes | [2] No |
| [1] Yes | [2] No |
| [1] Yes | [2] No |
| [1] Yes | [2] No |

72. Did a doctor ever tell you that you have any other health condition(s)?

- [1] Yes (Answer q. 73)
- [2] No (Skip to q. 74)

73. What are these other condition(s)?

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74. Please choose the response that best describes your employment status:

- A) employed for wages
- B) self-employed
- C) out of work for  $\leq 1$  year and looking for work
- D) out of work for  $> 1$  year and looking for work
- E) homemaker
- F) student
- G) retired
- H) unable to work

- [1] Yes [2] No (Answer q. 75)
- [1] Yes [2] No (Answer q. 75)
- [1] Yes [2] No (Skip to q. 76)
- [1] Yes [2] No (Skip to q. 76)
- [1] Yes [2] No (Skip to q. 76)
- [1] Yes [2] No (Skip to q. 76)
- [1] Yes [2] No (Skip to q. 76)
- [1] Yes [2] No (Skip to q. 76)

75. In an average week, about how many hours do you work on your job?

\_\_\_\_\_ # of hours

76. How many people live in your household, including yourself?

— —

77. Do you own or rent your home/apartment?

- [1] Own
- [2] Rent

78. What is your monthly mortgage payment/rent?

\$ \_\_\_\_\_

79. Have you ever smoked more than 100 cigarettes in your lifetime?

- [1] Yes
- [2] No

80. Have you ever exercised at least 3 times per week?

- [1] Yes (Answer q. 81)
- [2] No (Skip to q. 82)

81. Do you exercise at least 3 times per week now?

- [1] Yes
- [2] No

Thank you for completing this questionnaire. Your opinions can help us to improve the health care we provide. To show you our appreciation of your time spent completing this survey, we will mail you a \$5 Blockbuster Video gift certificate. Would you like us to send you a copy of the survey results (*Interviewer records participant's response*)

**Focus Group Moderator's Guide  
Perceptions of Cancer Screening**

**Facilitator: Marvella Ford  
Assistant: Danica Dixon  
Recorder: La-Kesha Parrish**

**October 26, 2000  
6:00 - 8:00 p.m.**

**I. WARM-UP AND EXPLANATION (10 minutes)**

**A. Introduction**

1. Good evening. My name is Marvella Ford. I work here at Henry Ford Health System. This is Danica Dixon. She will be the assistant this evening. La-Kesha Parrish is our recorder. Danica and La-Kesha also work here at HFHS.
2. Thanks for coming.
3. Your presence and participation are important. Your thoughts and comments about the questionnaire will be valuable in helping to provide future information on health issues.

**Purpose**

1. What we are doing here this evening is called a focus group. It's a discussion to find out your opinions -- like a survey.
2. I am interested in all of your ideas, comments and suggestions.
3. Each of you is very important and all of your comments -- both positive and negative -- are welcome.
4. There are no right or wrong answers.
5. Please speak up -- even if you disagree with someone else here. It important that I hear what each of you thinks.

**B. Procedure**

1. We will be audiotaping and videotaping our discussion. Everything you say is important to us, and we want to make sure we don't miss any comments. Later we'll go through all of your comments and use them to prepare a report on our discussion. However, all of your comments are confidential and will be used only for research



purposes. Nothing you say will be connected to your name. Also, if any questions make you uncomfortable, feel free not to answer them.

2. You don't have to wait for me to call on you but please speak one at a time, so the tape recorder can pick up everything.
3. We have many topics to discuss so I may change the subject or move ahead. Please stop me if you want to add anything.

**C. Self-Introductions (Ice Breaker)**

1. Please tell us your name and describe the car of your dreams.

**II. QUESTIONNAIRE**

1. **Please look at the first page of the survey.**

Are the statements on this page clear?

If so, what makes these statements clear?

If not, which words would you use to make the statements clearer?

2. **Now, please turn to page 2 of the survey.**

Are the instructions on how to complete this table clear?

If not, which words would you use to give instructions for completing this table?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Now please look at questions (a) - (u) on pages 2-3 of the survey. Are these questions clear?

Which questions are clear?

What makes these questions clear?

Which questions are not clear?

What makes these questions unclear?

How would you ask these questions to make them clearer?

How comfortable would you feel about completing questions (a) - (u)?

What makes you feel comfortable or uncomfortable about completing these questions?

**3. Now, let's turn to questions 2-10 on page 3.**

Are any of questions 2-10 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 2-10?

If you think it would be hard, what would make these questions easier to fill out?

If you think it would be easy, what makes them easy to fill out?

Is it clear to you that if you answer "NO" to question 4, you should go to question 6?

Is it clear to you that if you answer "NO" to question 6, you should go to question 8?

Is it clear to you that if you answer "NO" to question 8, you should go to question 10?

How comfortable would you feel in answering questions 2-10?

What makes you feel comfortable or uncomfortable about answering these questions?

**4. Now, let's look at questions 11 and 12 on page 4.**

Are questions 11 and 12 clear to you?

If not, which words would you use to ask questions 11 and 12?

How comfortable would you feel in answering questions 11 and 12?

What makes you feel comfortable or uncomfortable about answering these questions?

**5. Let's turn now to questions 13-24 on pages 4 and 5.**

Are any of questions 13-24 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 13-24?

If you think it would be hard, what would make these questions easier to fill out?

If you think it would be easy, what makes them easy to fill out?

Is it clear to you that if you answer "NO" to question 13, you should go to question 15?

Is it clear to you that if you answer "NO" to question 15, you should go to question 17?

Is it clear to you that if you answer "NONE" to question 19, you should go to question 21?

Is it clear to you that if you answer "NONE" to question 21, you should go to question 23?

Is it clear to you that if you answer "NONE" to question 23, you should go to question 25?

How comfortable would you feel in answering questions 13-24?

What makes you feel comfortable or uncomfortable about answering these questions?

**6. Let's turn now to questions 25-30 on page 5.**

Are any of questions 25-30 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 25-30?

If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 25-30?

What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 25, you should go to question 27?

Is it clear to you that if you answer "DON'T KNOW" to question 25, you should go to question 27?

Is it clear to you that if you answer "NO" to question 27, you should go to question 29?

Is it clear to you that if you answer "DON'T KNOW" to question 27, you should go to question 29?

Is it clear to you that if you answer "NO" to question 29, you should go to question 31?

Is it clear to you that if you answer "DON'T KNOW" to question 29, you should go to question 31?

**7. Now, let's look at the first table on page 6.**

Are the instructions on how to fill out the table clear to you?

If not, how could they be made clearer?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Are the words in the table clear to you?

If not, which words would you use to describe these things?

**8. Now, let's look at the second table on page 6.**

Are the instructions on how to fill out the table clear to you?

If not, how could they be made clearer?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Are the words in the table clear to you?

If not, which words would you use to describe these things?

**9. Let's turn our attention now to questions 33-44.**

Are any of questions 33-44 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 33-44?

If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 33-44?

What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 34, you should go to question 36?

Is it clear to you that if you answer "NO" to question 38, you should go to question 40?

Is it clear to you that if you answer "NONE" to question 42, you should go to question 44?

**10. Now, let's look at the table on page 9.**

Are the instructions on how to fill out the table clear to you?

If not, how could they be made clearer?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Are the words in the table clear to you?

If not, which words would you use to describe these things?

**11. Let's turn now to questions 46-61.**

Are any of questions 46-61 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 46-61?

If you think it would be hard, what would make these questions easier to fill out?

If you think it would be easy, what makes them easy to fill out?

Is it clear to you that if you answer "NO" to question 47, you should go to question 49?

Is it clear to you that if you answer "NO" to question 51, you should go to question 53?

Is it clear to you that if you answer "NO" to question 55, you should go to question 57?

Is it clear to you that if you answer "NO" to question 58, you should go to question 60?

Is it clear to you that if you answer "NO" to question 60, you should go to question 63?

How comfortable would you feel in answering questions 46-61?

What makes you feel comfortable or uncomfortable about answering these questions?

**12. Now, let's look at questions 63-70.**

Are any of questions 63-70 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 63-70?

If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 63-70?

What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 64, you should go to question 66?

**13. Now, let's look at questions 71-81.**

Are any of questions 71-81 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 71-81?

If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 71-81?

What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 72, you should go to question 74?

Is it clear to you that if you answer "NO" to question 80, you should go to question 82?

**14. Now, let's talk about different ways the survey might be completed.**

If the survey were mailed to your home, do you think you would complete it?

Do you think you would mail your completed survey back in a postage-paid envelope?

If someone called you to ask you the survey questions over the telephone, do you think you would complete it?

How would you rather complete this survey:

3. At home and return it in a postage-paid envelope?
4. Over the telephone with questions asked by a trained staff person?
3. In person with questions asked by a trained staff person?

**III. GENERAL PERCEPTIONS OF HEALTH AND HEALTH SERVICES**

Do you think that people who have regular check-ups by their doctor need to worry about getting cancer?

What makes you say this?

Do you have difficulty now in getting regular health care?

If so, what are some of the problems you are facing (Probe: waiting time to get an appointment; transportation problems; cost; time away from work)

Do you think that testing for cancer should be included as part of the physical exam done by your doctor?

What makes you feel this way?

Do you think that doctors and other health care providers should talk to Black men about their cancer risk?

(If yes, probe: What kinds of things do you think doctors and other health care providers should say to Black men about their cancer risk?)

Does your doctor talk to you about your risk of getting cancer?

(If yes, probe: What kinds of things does your doctor talk to you about, in terms of your risk of getting cancer?)

What could your doctor do to encourage you to get screened (or checked) for cancer?

(Probe: verbal recommendations and/or letters suggesting screening)

Do you think that health care clinics and hospitals are open at convenient times for cancer screening (or getting checked for cancer before you've ever had it)?

(If not, probe: What could be done to make the times more convenient for people to get cancer screening?)

Do you think that using t.v., radio, newspaper and magazine ads to encourage Black men to get screened (or checked) for cancer would be effective?

(Probe for reasons why or why not: Let's start with t.v. ads...Now, let's talk about radio ads.) (Probe: If men think ads would be effective say: What should these ads look or sound like? Who should be in them?)

How accurate do you think that the results of cancer screening tests are?

How likely do you think it would be for you to have cancer without having any signs or symptoms?

Do you know someone who has had cancer?

Do you think cancer can be cured if it is found early enough?

What makes you feel this way?

Do you think that people who have had cancer can live a normal life?

What makes you feel this way?

Do you think that your life would be better if you were screened (or checked) for cancer than it would be if you were not screened (or checked) for cancer?

(Probe: In what ways would your life be better? In what ways would your life not be better?)

How do you think that being African American affects your chances of getting cancer?

What do you think your risk is of getting cancer, compared to other men your age?

**Thank you very much for your comments tonight. They were very helpful.**



### **Focus Group Two: Results**

Eleven men participated in the focus group. These men ranged in age from 53-81 years, with a mean age of 68.7 years. The age of the men was fairly evenly distributed by decade.

As with the data from Focus Group 1, content analysis of the focus group transcripts was conducted. Following the approach used by Vuckovic, Ritenbaugh, Taren, & Tober,<sup>24</sup> transcripts were coded to index categories of responses. The transcripts were independently coded by the investigators and were checked for accuracy against notes taken during the focus groups.<sup>25</sup> The coding process provided a systematic approach to identifying themes in the data.<sup>26</sup> Statements identified from the data were open coded and grouped into conceptual categories, themes or axial codes by consensus among the investigators.<sup>26,26-28,28</sup> Themes related to survey questions that were common across both focus groups were identified, as well as themes unique to a particular focus group. The focus group data analysis revealed the following themes. Comments related to each them reflect statements made by unique individuals. Multiple comments by the same individuals are not include as separate statements.

Themes emerging from Focus Group 2 are shown in Table 12. This table shows that these themes include willingness to provide information to help others, the clarity of the language on the survey cover page, the clarity of the language included in Table 1 of the survey, a suggestion to change the language in Table 1 of the survey, lack of clarity regarding the manner in which Table 1 of the survey should be completed, the clarity of language of a number of additional survey items, experiencing symptoms as motivation for previous cancer screening, and overall level of comfort with providing the information requested in the survey.

Themes shown in Table 12 also include the social support and influence factors of preferred ways of learning about cancer screening, urging other focus group participants to get screened for cancer, suggested means of sharing cancer-related information with other African American men and wives as motivators to obtain cancer screening.

Cognitive/psychological factors shown in Table 12 include lack of knowledge regarding cancer, lack of belief in the efficacy of cancer screening tests, belief in the efficacy of cancer screening tests, the role of African American males' beliefs regarding health and health care, the lack of association between cancer risk behavior and cancer, lack of knowledge of cancer risk factors, knowledge of cancer risk factors, lack of knowledge of cancer symptoms, uncertainty regarding the role of cancer early detection in reducing cancer mortality, seeking knowledge as motivation for previous cancer screening, knowledge of cancer incidence among African American men, lack of belief in the efficacy of cancer screening, belief in the efficacy of cancer screening, belief in the efficacy of cancer early detection, lack of belief in physician efficacy, belief in physician efficacy, fear as a barrier to cancer screening, knowledge of diet as a health risk factor, lack of understanding of the term "flexible sigmoidoscopy", lack of understanding of the term "PSA test" and understanding the role of family history as a cancer risk factor.

Programmatic/systemic factors shown in Table 12 include the suggestion to include screening as part of routine health care, overcrowded clinics, the role of health insurance coverage and the cost of cancer screening, the role of health care providers in cancer surveillance, the gender of physicians in relation to cancer screening and the historic exclusion of African Americans from traditional health care settings.

Table 12. Themes Emerging from Focus Group 2

Theme	Comments Related to the Theme
Willingness to Provide Information to Help Others	<ul style="list-style-type: none"> <li>□ "The questions and answers that we give, are they going to be used in other surveys or part of the (health) system to make it run smoother?"</li> <li>□ "I would share anything I have or know to help anybody"</li> <li>□ "I feel the same way"</li> </ul>
Clarity of Language on Survey Cover Page Statement "We are interested in your opinions about your health and the health care that you receive. All of the information that you provide will be kept confidential"	<ul style="list-style-type: none"> <li>□ "(All) Yes, the statements are clear"</li> <li>□ "It is the way the sentences are structured. Since you are interested in everybody's opinion on individual health and the individual health care they receive"</li> </ul>
Clarity of Language in Table 1	<ul style="list-style-type: none"> <li>□ "(All) Looks easy to answer"</li> <li>□ "(It looks easy because of) the way it is structured and the way it is in the boxed and numbered 1-5. It appears to be easy in terms of if you follow the directions, and you can read you should not have a problem completing it. It is laid out pretty self-explanatory"</li> <li>□ "Five means stronger, graded in a degree on down... I think they (the questions in Table 1) are clear because it is up to the individual to voice your opinion. It's based on you personally"</li> <li>□ "All of them (the questions in Table 1) are clear to me"</li> <li>□ "(The survey) asks you the question direct"</li> <li>□ "I like the way they word this. What we are reading they are not asking you questions, they are looking for you to voice your own opinion... Everything in here seems to be simple to me"</li> </ul>
Suggestion to Change the Language in Table 1 "(Moderator): Do you think it sounds like there is some question as to whether we are looking for people's opinions or knowledge. Do you think we should say again on this page that we are interested in your opinions (and are not testing knowledge)?"	<ul style="list-style-type: none"> <li>□ "(All) "I think so"</li> </ul>

Theme	Comments Related to the Theme
Lack of Clarity Regarding How to Complete Table 1	<input type="checkbox"/> "The one (answer) that you pick, do you circle it or what?" <input type="checkbox"/> "These questions, can you just put yes or no?"
Clarity of Language of Questions 13-25	<input type="checkbox"/> "It would be easy to answer these questions" <input type="checkbox"/> "They are simple questions"
Experiencing Symptoms as Motivation for Previous Cancer Screening	<input type="checkbox"/> "Didn't want to go (to get screened for cancer). I felt good, didn't want to go... It's just like you (another focus group participant) said, 'It's a form of ignorance', just like you said. I should have had a check-up but I didn't" <input type="checkbox"/> "See, that's the whole thing right there. As long as you feel good you figure there is nothing wrong; you're not going there to waste time in the doctor's office"
Overall Level of Comfort with Providing the Information Requested in the Survey	<input type="checkbox"/> "Very comfortable" <input type="checkbox"/> "Ok"

Theme	Comments Related to the Theme
Social Support and Influence Factor: Preferred Ways of Learning about Cancer Screening	<ul style="list-style-type: none"> <li>□ "TV ad"</li> <li>□ "I think booklets and pamphlets"</li> <li>□ "I think booklets and pamphlets, because other than that you might miss it (the information)"</li> <li>□ "Also, if you have ever been there to the clinic there in ____ Hospital, you know in the lobby there, one time when they were having the screening they had the videotapes. Those tapes you know while you are sitting there waiting are very informative"</li> <li>□ "I don't think there is enough information about what would motivate African-American men to get checked. That is something that ought to be, everywhere you look they ought to be telling you to do that, you don't see it"</li> <li>□ "I think what we have to do is get that (cancer) information in their face some kind of way. Every time they look"</li> <li>□ "Put a pamphlet (with cancer information) behind your time card, so when you pick up your time card (you will see the cancer information)"</li> <li>□ "They (African American men) really do need to be informed, 'You go and get cured, find out about these things because they can be cured'. I am a living example of it. I have had all kinds of cancer and I'm still here... (Having a show on television with cancer survivors like the men in this room talking about their experiences who had been diagnosed 10 years ago, 12 years ago)... That would save many lives. That would really go far, cancer is not the last word, cure is the last word"</li> <li>□ "Some of them (young people) watch those rap shows. You can throw it (cancer information) in there"</li> <li>□ "(At) ____ Family Center, I guess the older people are in there, most of them are retirees. And they go for preventive medicine, prescriptions and all kinds of stuff. That would be the place to start as far as the pamphlets. Ok, you got them all in there; you almost got a captive audience because they eat lunch there. You know, you take five minutes at lunchtime to say, 'I have a message for you', before you let them eat. Now you've got them captured, now you've got their attention, ok and you tell them and you keep stressing this (cancer information)"</li> </ul>

Theme	Comments Related to the Theme
Social Support and Influence Factor: Preferred Ways of Learning about Cancer Screening (cont'd)	<ul style="list-style-type: none"> <li>□ "If they (other Black men) had seen the conversation we had tonight, you would have these same conversations in all the work places around the country. Tomorrow morning they will be saying, 'Did you hear what the brother said last night?' Then they would start thinking, 'Maybe I need to go do that (get screened for cancer).' So this is where it needs to be, not in a back room somewhere. It should be right out so the public can hear it, us talking among ourselves is going no where but back to our homes, but if we're in a position where could inform them like that I think it would be more helpful..."</li> <li>□ "Any way that you could get this (information discussed in the focus group, in a similar group discussion format) out (to the public via the television news media"</li> </ul> <p>Disagreement:</p> <ul style="list-style-type: none"> <li>□ "Well, that television really doesn't give you too much 'cause they are working on time, time means everything, and you don't just get it"</li> <li>□ "Young people don't watch television, bunch of young people don't watch television, don't read no newspaper"</li> <li>□ "I don't know what media we would use to do that (get cancer information to African American men). I mean we can't use the TV because we can't afford the time. Everybody does not read the paper, everybody does not read magazines. You can't get all the ministers to talk about it for five minutes in church. You got to find a way to get the information to them and I don't know how you would do that"</li> </ul>
Social Support and Influence Factor: Focus Group Participant Urged Other Participants to Get Screened for Cancer	<ul style="list-style-type: none"> <li>□ "I tell them all if you haven't been checked for prostate cancer, go get checked"</li> </ul>

Theme	Comments Related to the Theme
Social Support and Influence Factor: Suggested Means of Sharing Cancer-Related Information with Other African American Men	<ul style="list-style-type: none"> <li>□ "If they (other Black men) had seen the conversation we had tonight, you would have these same conversations in all the work places around the country. Tomorrow morning they will be saying, 'Did you hear what the brother said last night?' Then they would start thinking, 'Maybe I need to go do that (get screened for cancer).' So this is where it needs to be, not in a back room somewhere. It should be right out so the public can hear it, us talking among ourselves is going no where but back to our homes, but if we're in a position where could inform them like that I think it would be more helpful..."</li> <li>□ "Any way that you could get this (information discussed in the focus group, in a similar group discussion format) out (to the public via the television news media"</li> <li>□ "And they (men watching at home) would sit there and look at this and they would identify (with the men in the discussion)... These are people just like them"</li> <li>□ "It would help a lot of people"</li> <li>□ "That would save a lot of lives, because they would discuss this. I think you gentlemen have some good ideas"</li> </ul>
Social Support and Influence Factor: Wife as Motivator to Receive Cancer Screening	<ul style="list-style-type: none"> <li>□ "Here is a man that's got insurance he never goes to see the doctor until his wife says ok you are sick go, why doesn't he go on his own, why doesn't say hey I'm hurting I'm going to go see the doctor. Nine times out of ten, he is not going to do that"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Lack of Knowledge Regarding Cancer	<ul style="list-style-type: none"> <li>□ "It's (the language in Table 1) fairly simple but how much do you know about cancer? Like "J" for instance, it says, 'Exercising regularly affects your chances of developing cancer'. How do I know if I exercise at all it will affect my chances of getting cancer? I don't have that knowledge... I don't know whether exercise help me or not. I know it generally helps you in most areas but I don't know if it would help me in regards to cancer."</li> <li>□ "I know people who exercise, eat the right foods and still come down with cancer. No smoking, drinking, or a harsh diet and they still got cancer"</li> </ul>
Cognitive/Psychological Factor: Lack of Belief in the Efficacy of Cancer Screening Tests	<ul style="list-style-type: none"> <li>□ "All results of cancer screening tests are not accurate. I think it depends on the people who are administering the test and the people that are solving the results of the test"</li> <li>□ "Too much misdiagnosed. You hear and see it all the time, people going to the doctor and they checked you, they are treating them for arthritis, for this and that, and wind up having bone cancer..."</li> </ul>
Cognitive/Psychological Factor: Belief in the Efficacy of Cancer Screening Tests	<ul style="list-style-type: none"> <li>□ "That's just not the way I was raised. I've been going to the doctor all my life. I go for check-ups. All my kids went. My wife came up in the medical field, so I always believed in going to the doctor, and I encourage all my friends to. I tell them all, go get a check-up, go get this here, they told my wife, how did they find that cancer, she had that cancer call pre-cancer in her lung, because she went to the doctor. Even they told her at ____ Hospital that you never find this kind of cancer this early but that check-up, she and I believe in that, and that is the way we think all the time, that if was not for that she'd be gone, me too"</li> <li>□ "That's right you'd be gone, too"</li> </ul>
Cognitive/Psychological Factor: Role of African American Males' Beliefs Regarding Health and Health Care	<ul style="list-style-type: none"> <li>□ "Traditionally, African American men have not gone to doctors. You know a lot of you have worked while you are sick, and you won't go until it is too late or you end up in the hospital by that time it is too late. Why don't you go in for a check-up twice a year? You won't do it"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Role of African American Males' Beliefs Regarding Health and Health Care (cont'd)	<ul style="list-style-type: none"> <li>❑ "He's (African American men are) too macho (to see a doctor). I had Blue Cross all my life but it was 10 or 15 years before I would go and see a doctor but I had the insurance there, but I wouldn't go. And it's a lot of other people that way, too... You start feeling bad, that's when I started going (to see a doctor)"</li> <li>❑ "They're too much man to go to the doctor, (it might) make them look puny"</li> <li>❑ "You shouldn't look at it negatively; it's just a fact of life (that African American men do not like going to see a doctor)"</li> <li>❑ "See I just lost a friend three weeks ago. She (the friend's wife) died over in ____ Hospital, and he retired along with me you know but a year before I did. And he and his wife sat at home and drank, and drink put him in the hospital in intensive care and in one week he was gone. Now I did not know that until he called and told me (he was in the hospital) and I kept beating my head against a wall, (asking myself), 'Why didn't you get him out and make him go to the doctor?' Why do we (black men) sit around until it gets to be too late?"</li> </ul>
Cognitive/Psychological Factor: Lack of Association Between Cancer Risk Behavior and Cancer	<ul style="list-style-type: none"> <li>❑ "I smoked for 30 years and never had any cancer"</li> </ul>
Cognitive/Psychological Factor: Lack of Knowledge of Cancer Risk Factors	<ul style="list-style-type: none"> <li>❑ "If I don't know that I am at a reduced risk (for cancer) how would I know if I am at a greater risk (for cancer compared to other men)?"</li> <li>❑ "How would I know if compared to other men of my age, how would I know if my risk is far greater?... I would almost have to say I have the same risk for the same age. If we are the same age, we have the same risk"</li> </ul>
Cognitive/Psychological Factor: Knowledge of Cancer Risk Factors	<ul style="list-style-type: none"> <li>❑ "I think I have reduced risk because I haven't smoked in 50 years, I eat fairly good"</li> </ul>
Cognitive/Psychological Factor: Lack of Knowledge of Cancer Risk Factors	<ul style="list-style-type: none"> <li>❑ "You don't have any symptoms, I didn't have any symptoms. I just stopped by the hospital to get checked and they told me, and that is when they found out I had colon cancer. And there was nothing hurting me then and there is nothing hurting me now... I don't know what the signs would be. But I didn't have any symptoms"</li> </ul>



Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Lack of Knowledge of Cancer Risk Factors (cont'd)	<ul style="list-style-type: none"> <li>□ "I would think that in some cancers, you have no feeling (symptoms) but at other times, there would have to be some type of pain or something that was abnormal"</li> <li>□ "There is no pain in prostate cancer. I had cancer and had no idea I had it, they operated on me for my bladder and they found out I had prostate cancer"</li> <li>□ "My doctor kept on telling me that when I get of age I should go on in and have a check-up. So I said, 'Well, I will have the check-up'. When the doctor checked me the next thing he told me is that I got it (prostate cancer). So I went for the operation, but I didn't listen to the doctor, and he kept on telling me that I been walking around not knowing I had it, but I had no warning or anything"</li> <li>□ "My wife had lung cancer and they removed her lung (and) she didn't know she had cancer... I had three different kinds of cancer and I haven't felt anything (any symptoms)"</li> </ul>
Cognitive/Psychological Factor: Uncertainty Regarding the Role of Cancer Early Detection in Reducing Cancer Mortality	<ul style="list-style-type: none"> <li>□ "It says here that cancer if found early it can be cured. Is that true with all cancers?"</li> </ul>
Cognitive/Psychological Factor: Seeking Knowledge as Motivation for Previous Cancer Screening	<ul style="list-style-type: none"> <li>□ "If you have cancer, you have cancer and I want to know (if I have cancer)"</li> <li>□ "I have been told three times that I have cancer, and each time it's through the roof, you don't want to hear about it, but I am glad I heard it. They (doctors) told me I had six months to live. I didn't want to hear that but I'm glad they told me that so I got me some help, because I don't think that's a hang-up. I think that would be nonsense to not know. I want to know what is wrong with me"</li> </ul>
Cognitive/Psychological Factor: Knowledge of Cancer Incidence Among African American Men	<ul style="list-style-type: none"> <li>□ "Afro-American men, there is a greater incidence of cancer"</li> </ul>
Cognitive/Psychological Factor: Lack of Belief in the Efficacy of Cancer Screening	<ul style="list-style-type: none"> <li>□ "When I had mine (flexible sigmoidoscopy) they didn't find anything and I told them that (they would not) before they went up there"</li> <li>□ "My biggest fear the fact of going to the doctor and not being diagnosed and going on yearly exams and they don't find it or somehow or another they miss it"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Belief in the Efficacy of Cancer Screening	<ul style="list-style-type: none"> <li>□ "I was checked a couple weeks ago. Actually I get checked every year. So far I haven't been or had cancer"</li> <li>□ "Same thing here"</li> <li>□ "It's worthwhile"</li> <li>□ "Well I have had several of them (flexible sigmoidoscopies) but I think they were good and worth it because they found some polyps in me that were cancerous and some that weren't. So without that they would not have been able to detect it (cancer)"</li> <li>□ "It (the flexible sigmoidoscopy procedure) doesn't miss a thing. After that they told me to come back in three years"</li> </ul>
Cognitive/Psychological Factor: Belief in Efficacy of Cancer Early Detection	<ul style="list-style-type: none"> <li>□ "I know my doctor told me that it is not about whether they can cure it. It is about whether they can catch it in time. You've got to catch it in time. That is so important"</li> </ul>
Cognitive/Psychological Factor: Lack of Belief in Physician Efficacy	<ul style="list-style-type: none"> <li>□ "I think there is a fear there-the fact that when you are looking at a person and they are checking you and they only diagnose certain things or either don't tell you every thing that is going on so you get to thinking, hey if he wont tell me or she wont tell me, I don't care too much for that doctor so you don't go to the doctor period unless you are hurting"</li> </ul>
Cognitive/Psychological Factor: Belief in Physician Efficacy	<ul style="list-style-type: none"> <li>□ "We have to trust doctors' technology, we have to accept that. At least I feel like that. Because you know, I whole-heartedly accept what doctors tell me"</li> <li>□ "I'm going to get a healing for myself or a cure for myself and if tell somebody I got the cure then maybe they will tell somebody"</li> <li>□ "I was taking 37 treatments here at ____ Hospital. Every morning we would have a group like this one here, it would be about 50 of us taking these treatments. Now a lot of those guys told me if they had only known, once that cancer gets into your bones they can't cure you. If you inform them and they get to these doctors they can be cured"</li> </ul>
Cognitive/Psychological Factor: Fear as a Barrier to Cancer Screening	<ul style="list-style-type: none"> <li>□ "Most people I talk with seem to be afraid to talk about cancer with you or me"</li> <li>□ "They don't want to talk about it"</li> <li>□ "But most men ... think it is a shame to have cancer and they look at you like its got a scorn on you or something...But don't be afraid to tell somebody that you got cancer and you went to get a treatment and the doctor said you're cured"</li> </ul>

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Fear as a Barrier to Cancer Screening (cont'd)	<ul style="list-style-type: none"> <li>□ "Some people ... are embarrassed and afraid like they don't want to talk (about cancer and cancer screening), so that is part of it, too"</li> <li>□ "I want to know also (whether he has cancer) but I used to have that fear though, I have had that fear"</li> <li>□ "I fear the cancer; I fear all these other things"</li> <li>□ "No when I was taking my treatments, I was taking 37 treatments here at ____ Hospital. I have cancer right now and my doctors tell me I am going to die with something else, 'It's not going to be the cancer that kills you'. I don't fear cancer like I used to"</li> <li>□ "I think it is up to the ones that don't fear to inform the ones that do fear. And I think that we should get help from the professional people like yourself to help us. You people have the power to do it, we don't. We can tell you our wishes, I would be glad to share my experience anywhere"</li> </ul>
Cognitive/Psychological Factor: Knowledge of Diet as a Health Risk Factor	<ul style="list-style-type: none"> <li>□ "I think it's our eating habits (that put African American men at risk for health problems)"</li> <li>□ "When you look at high blood pressure in blacks, you eat that greasy food all your life, this is what you like, you go in there, they tell you to cut back on your salt, cut back on your pork, cut back on your eggs, you may do it but how many others will? How many others are going to go in there and prescribe some medication take that medication everyday to bring it down?"</li> </ul>
Cognitive/Psychological Factor: Lack of Understanding of Term "Flexible Sigmoidoscopy"	<ul style="list-style-type: none"> <li>□ "I think they (words) are clear, but for me I think you got some words here that are foreign to me"</li> <li>□ "Question, what is it?"</li> <li>□ (After hearing description of the flexible sigmoidoscopy) "I have had that procedure done; I just didn't know what they call it"</li> </ul>
Cognitive/Psychological Factor: Lack of Understanding of Term "PSA Test"	<ul style="list-style-type: none"> <li>□ "I don't know what it is"</li> <li>□ "The PSA is not a cancer that is in your blood. When I got my treatments (for prostate cancer) my PSA was 8. Two weeks ago here at ____ Hospital it was 4, so it is not a cancer that is in your blood"</li> </ul>
Cognitive/Psychological Factor: Understanding the Role of Family History as a Cancer Risk Factor: "Do You Think That People Who Have Had Cancer in Their Family Are More Likely than Other People to Get Cancer?"	<ul style="list-style-type: none"> <li>□ "I think so. I do think it runs in the family"</li> <li>□ "You don't have to get cancer just because someone else in the family got it"</li> <li>□ "I do think it runs in the family... All my people died of cancer. I had five brothers and all of them died of cancer and my daddy, and I got cancer and I do believe that it runs in the family"</li> <li>□ "I would agree to that"</li> </ul>

Theme	Comments Related to the Theme
Programmatic/Systemic Factor Related to Cancer Screening: Need for Screening Needs to Be Included as Part of Routine Health Care	<ul style="list-style-type: none"> <li>□ "When you go in for a regular check-up the doctors check your blood pressure and all those other things that they normally check, why isn't cancer screening part of that?"</li> <li>□ "You can't know what they've taken blood tests for, what they are checking for and what they are not checking for. You can still have cancer (and not know it), is what I am saying"</li> <li>□ "Well you don't know that for sure (doctors check for cancer during check-up), because you go there to get your check-up... They don't tell you all those things"</li> <li>□ "They don't tell you what they are checking for...you have to ask for it (cancer screening)"</li> <li>□ "You have to ask"</li> <li>□ "They should just automatically do that (check for cancer during routine examination"</li> <li>□ "Some doctors are more thorough than others"</li> </ul> <p>Disagreement:</p> <ul style="list-style-type: none"> <li>□ "I was in there (the hospital) last month and they checked for cancer while I was in the hospital"</li> </ul>
Programmatic/Systemic Factor Related to Cancer Screening: Overcrowded Clinics	<ul style="list-style-type: none"> <li>□ "I would also add that most men middle age and younger black men are short (of) patience. How many times have we all gone into the clinic and the clinic was full and mostly what you saw in the clinic was women and kids and the men were there, they were out in the car waiting because they brought them (the women and children) up there (to the clinic). You did not see them sitting in there waiting to see the doctor"</li> </ul>
Programmatic/Systemic Factor Related to Cancer Screening: Health Insurance Coverage and the Cost of Cancer Screening	<ul style="list-style-type: none"> <li>□ "I was also told that it (flexible sigmoidoscopy) was a very costly type of exam and the insurances do not allow you to go in routinely to take this type of exam"</li> <li>□ "I saw something on TV about the insurance, how much they pay and how much the cost of the test, too much is misdiagnosed"</li> <li>□ "Somebody needs to take a look at thorough patient care. I don't care how much money is involved. Somebody is always talking about how the HMO will only pay this amount. They need to stop playing with people's lives because of money. They diagnosed this lady three different times before they finally said it was cancer but it was too late she was too far-gone. That is what is scary, not the cancer"</li> </ul>

Theme	Comments Related to the Theme
Programmatic/Systemic Factor Related to Cancer Screening: Health Insurance Coverage and the Cost of Cancer Screening (cont'd)	<ul style="list-style-type: none"> <li>□ "If they have to check all those things (screens for cancer), that will take more time and more lab work and that is where all that money comes in. People may not want to believe but a lot of it weighs on that. Its bad to say but it is true"</li> <li>□ "I think that there are a lot of black individuals that don't come in for an exam period, so therefore you have to be able to get to them and then ... a lot of them don't have health insurance"</li> <li>□ "We (black people) have not had the good insurance (that facilitate cancer screening)"</li> <li>□ "We have a lot of homeless here in the city that are not getting any kind of care, and so therefore with a shortage of facilities and no health care and then they are in and out of these rescue missions, you know, being fed. They are getting a meal, put together by these rescue missions in the neighborhoods but there again they are not getting any type of health care"</li> </ul>
Programmatic/Systemic Factor Related to Cancer Surveillance: Role of Health Care Providers in Cancer Surveillance	<ul style="list-style-type: none"> <li>□ "I have an appointment tomorrow for a check-up, because they check me every 90-days now; every 90 days to see how my cancer is doing - leukemia"</li> </ul>
Programmatic/Systemic Factor: Gender of Physicians As Related to Cancer Screening	<ul style="list-style-type: none"> <li>□ "I have had a female doctor for so long ... the female doctor I have, they do not check as a man would check a man. So at the time I got my prostate checked in the past five years was through the screening (outside of his health care location), so the only thing that is going on in my mind now is if they stop that free screening, do I have to find me another male doctor or go back to the clinic where I was going before see a male doctor to get a check-up? A lot of time they (female doctors) don't check you. They will come in and say, 'Well, how are you doing?' and ask if anything is bothering you." And they will go as far as they are going to go being a female with a male patient. I'm not saying women are not good doctors, I'm just saying that they don't catch it when I do come for the physical"</li> </ul>

Theme	Comments Related to the Theme
Programmatic/Systemic Factor: Gender of Physicians As Related to Cancer Screening (cont'd)	<input type="checkbox"/> "I had a female check my prostate and I would rather have a man. Those females are rough... It does not make a difference, but I'm just telling you which ones are rough" <input type="checkbox"/> "I would rather see a male (doctor)"
Programmatic/Systemic Factor: Historic Exclusion of African Americans from Traditional Health Care Settings	<input type="checkbox"/> "A whole lot of these things (health issues) we are suffering now come from our heritage. You have to look at things the way they really are. Our heritage dictates a lot of these things. A lot of these things we don't know to do (such as make adequate use of health services), and it comes from the way society has pushed us in a corner. I don't call it equal I am afraid of that word, it is kind of what you have been forced to accept... Why don't you have the money (to pay for health care)? Because you were ostracized and didn't have a chance to get it" <input type="checkbox"/> "And what was available to you" <input type="checkbox"/> "A lot of things come from the lack of money"

### KEY RESEARCH ACCOMPLISHMENTS

- An abstract describing the focus group results was submitted for presentation at the 2001 Annual Meeting of the Gerontological Society of America.
- An abstract documenting the design of the funded research was submitted for presentation at the 2000 meeting of the American Association for Cancer Research.
- Two focus groups assessing the perceptions of older African American men toward cancer screening were conducted.
- A manuscript describing the focus group results is being prepared and will be submitted by December 2001 to a peer-reviewed journal for publication consideration. An outline of the manuscript describing the focus group results has been completed. The outline is as follows:
  - A. Description of two themes:
    1. Development of a culturally appropriate instrument designed to assess perceptions of cancer screening among African American men
    2. Perceptions of cancer and cancer screening elicited from the focus group participants
  - B. Impact of the PLCO cancers on African American men
  - C. Relationship between perceptions of cancer and cancer screening and participation in cancer screening among African American men
  - D. Relationship between these perceptions and the development of culturally appropriate screening interventions designed to address these perceptions
  - E. Description of the process of developing the culturally appropriate instrument

1. Literature review to develop content areas for the instrument
  2. Focus Group 1 - designed to ascertain the validity of the content areas of the instrument for African American men
  3. Revision of the instrument based on the focus group results
  4. Focus Group 2 - designed to ascertain the validity of the terms and format used in the instrument for African American men
- F. Themes emerging from Focus Group 1
- G. Themes emerging from Focus Group 2
- H. Implications of the focus group results for the development of cancer screening interventions for African American men
- A manuscript describing the case management approach is being prepared and will be submitted by December 2001 to a peer-reviewed journal for publication consideration. An outline of the manuscript describing the case management approach has been completed. The manuscript will be submitted in November 2001 for publication consideration to the peer-reviewed journal, *Health and Social Work*. The manuscript outline is as follows:
    - A. Impact of the PLCO cancers on African American men
    - B. Description of the DOD Phase I case management intervention
    - C. Case studies 1 and 2
    - D. Implications of the findings for
      1. Developers of clinical trials
      2. The role of social workers in facilitating health services utilization among African American men
    - E. Conclusions
  - A presentation describing the case management approach is being prepared and will be presented in September 2001 to the Director of the Josephine Ford Cancer Center and to the Director of Epidemiologic Research at the Josephine Ford Cancer Center, Henry Ford Health Sciences Center. The presentation is the basis of the manuscript describing the case management approach.
  - Because of the nature of this study, Dr. Ford was invited to participate in the National Institutes of Health/National Cancer Institute, Division of Cancer Control and Population Sciences Workshop on Behavioral Intervention Research and Assessment for Colorectal Cancer Screening. This meeting took place December 9-10, 1999 in Washington, D.C. The purpose of the meeting was to assess the status of behavioral research related to colorectal cancer screening.
  - Dr. Ford was invited to participate in the National Institutes of Health/National Cancer Institute's Colorectal Cancer Progress Review Group Roundtable. The goal of the Roundtable, which took place January 5-7, 2000, in Washington, D.C., was to establish a national research agenda for colorectal cancer.
  - Dr. Ford was invited in 2000 to become a member of Member of the National Institutes of Health Risk, Prevention & Health Behavior IRG - Study Section 3. This National Institutes of Health Behavioral Health study section group meets three times per year to review proposals written by scientific peers.
  - A questionnaire has been developed that will assess perceptions of African American men toward cancer screening. The concepts in this questionnaire are being modeled after the concepts in the Preventive Health Model.<sup>5</sup> In a future study, the factor

structure of the newly developed questionnaire will be compared with the theoretical framework found in the Preventive Health Model.<sup>5</sup>

## REPORTABLE OUTCOMES

### *Manuscripts, abstracts, presentations:*

The following abstract was submitted in April 2001 for presentation consideration at the 2001 Annual Meeting of the Gerontological Society of America.

**Developing A Survey To Assess Cancer Screening Perceptions Of Older African American Men.** Jankowski M, Ford ME, Parrish L, Butler A, Vernon S, Swanson GM. Henry Ford Health System, RCMAR, 1 Ford Place, 3E, Detroit, MI 48202.

African American (AA) men have higher cancer incidence and mortality rates than Caucasian (C) men. Cancer screening perceptions influence screening behavior and early detection. The goals of this study were: (1) to validate, through focus groups, a survey assessing cancer screening perceptions of older AA men and (2) to describe the perceptions of focus group members. Survey items, derived from a literature review, were grouped into the cognitive/psychological (C/P) factors, social support and influence (SSI) factors and programmatic/systemic (P/S) factors of the Preventive Health Model. For each focus group, AA male patients aged 55+ years were randomly selected. Focus group #1 was held with 10 men ranging in age from 55-87 years, with a mean age of 73.4 years. The 11 men in focus group #2 had an age range of 53-81 years, with a mean age of 68.7 years. The survey items and wording were validated in the focus groups. During the focus groups, C/P factors of fear and anxiety regarding cancer diagnosis and lack of knowledge about screening tests and screening benefits were stated. Wives were noted as the most important SSI persons affecting screening behavior. Having a trusted health care provider and health insurance were cited as P/S screening-related factors.

An abstract describing the retention study was submitted on November 1, 1999 for consideration as a presentation at the American Association of Cancer Research Conference in April 2000. The abstract is described in the following paragraphs.

**Retaining African American Men in a Cancer Screening Trial: Challenges, Solutions, and Focus Group Results.** Ford ME, Swanson GM, Vernon S, Hill D, Jankowski M, Randolph V, Johnson CC. *Resource Center for Minority Aging Research and Josephine Ford Cancer Center, Henry Ford Health System, Detroit, MI 48202*

This presentation describes challenges faced in carrying out a retention study involving African American men and solutions to these challenges. The objective of the retention study, begun in July 1999, is to identify innovative methods for increasing the retention of African American men in prostate cancer screening trials. Retention, while important for all groups, is especially critical for African American men, given their often low representation in clinical trials. The specific aims are to evaluate the efficacy of an



intervention designed to retain African American men in the screening arm of the Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial at the Henry Ford Health System site, and to develop a culturally appropriate measurement instrument to assess perceptions of screening for these cancers among older African American men. The study population consists of African American men aged 55 and older living in the Detroit area. Blocked randomization methods were used to assign the men to the retention intervention or control group. A retention coordinator provides intense follow-up to the men in the intervention group and guides them through the PLCO Trial cancer screening processes. It is hypothesized that men in the intervention group will show higher screening adherence rates than men in the control group. An instrument to assess cancer screening perceptions among older African American men will be developed using focus group techniques. The results of these focus groups are described in the presentation.

## CONCLUSIONS

Issues related to the implementation of the behavioral intervention and other aspects of the study protocol

The behavioral intervention has been designed to overcome barriers to continued trial participation. The main element of the intervention is a retention coordinator, who establishes and maintains monthly telephone-based contact with PLCO Trial participants in the intervention arm of the study, and who serves as a source of information about relevant health and social services. This intervention is based upon the systems approach in the field of social work, in which a case manager serves as a link between clients and needed resources and resource systems by serving as a source of information about these resources and systems. While somewhat more limited in breadth than a traditional case manager, the retention coordinator nonetheless attempts to maintain a similar depth of personal relationships with the PLCO Trial participants as a case manager would with her or his clients.

Four barriers to the participation of minority populations in clinical trials have been identified by Swanson and Ward.<sup>29</sup> These are sociocultural barriers, economic barriers, individual barriers, and barriers inherent in study design, which can affect not only recruitment to cancer screening trials but also continued participation in these trials as well. The innovative telephone-based retention strategy administered by a retention coordinator has been designed to address these barriers to continued trial participation. Sociocultural Barriers - These barriers include fear and mistrust of federally sponsored projects. In the present study, the retention coordinator, a person of the same race as the study participants, aims to develop rapport with the participants and build a sense of trust with them. The retention coordinator provides participants and their spouses/partners with requested information pertaining to the PLCO Trial as well as other questions they have related to health and social services. Economic Barriers - These barriers are addressed in the proposed recruitment study. The retention coordinator serves as a clearinghouse for information related to older adults and their families, such as that provided by local Area Agencies on Aging and local senior centers. Addressing issues of

importance to participants may help to free them from some economic worries, thus allowing them to focus on their cancer trial participation. Individual Barriers - Individual barriers include denial and underestimation of personal vulnerability. It is hoped that the customized approach of the telephone calls from the retention coordinator will reduce individual barriers to participation as well as sociocultural barriers, as health issues pertinent to older African American men are addressed during these telephone conversations. Barriers Inherent in Study Design - The proposed study is designed to minimize barriers inherent in study design, which Swanson and Ward<sup>29</sup> point out can significantly reduce study participation rates. The retention coordinator guides the men assigned to the intervention arm of the study through the PLCO Trial screening processes.

### Challenges and Solutions

(a) Originally, the retention coordinator was only going to contact men assigned to the intervention arm of the present study. Existing PLCO Trial schedulers would make screening appointments for men assigned to the control arm of the study. However, one of the co-investigators pointed out the fact that this could serve to introduce bias into the study. The study protocol has been changed so that the retention coordinator now makes all of the contacts with all of the men in the study. This protocol change will help to reduce bias that might be associated with style differences in interacting with the study participants. The retention coordinator contacts the men in the intervention arm (n=301) by telephone on a monthly basis and also schedules yearly PLCO Trial cancer screening appointments for the men in the control arm (n=300) of the study.

(b) During the first two months of the study, the retention coordinator was not able to speak via telephone with 35 men because they were not available when she called. After some discussion, the research team made the decision that the retention coordinator would leave messages on the answering services of the men. In the message, the retention coordinator introduces herself as a resource person for the men, and lets them know that she will call them on a monthly basis, and that she is available to help them to find answers to questions they or their family may have. At the end of the message, the retention coordinator leaves her telephone number, and asks the participant to call her. The retention coordinator now leaves similar messages with all men she is not able to speak with directly when making the monthly calls, although she continues to call them throughout each month in an attempt to speak directly with them.

(c) In order to maximize the number of intervention group participants with whom the Retention Coordinator speaks directly each month, the process of mailing requested information has been delegated to a staff secretary. We did not expect study participants to ask for as great an amount of information as they are currently requesting. Information is being requested related to transportation, food services, recipes, medication, various diseases, literacy, housing, social security, and child care. For example, the retention coordinator has been asked by the spouses of study participants for information related to the participant's grandchildren. Because of the volume of information requested, the responsibility of mailing information to participants has been given to a staff secretary. The secretary now generates the cover letters accompanying the mailed materials. The

Retention Coordinator then signs the cover letters, and the completed information packets are then mailed by the secretary. During the planning stage of the study, the retention coordinator contacted a number of local agencies to receive information related to the services provided by these agencies. A file was developed listing the agencies and the services provided. This file serves as a source for locating information requested by study participants. Other sources of information include the Internet, the Yellow Pages, radio and television announcements, agency newsletters, and a directory of local human services. A listing of community resources used in the study is included in Appendix C.

(d) In a previous study involving recruitment of African American men to the PLCO Cancer Screening Trial, it was discovered that the men's female spouses/partners served as gatekeepers. If the women did not think their spouses/partners should participate in the PLCO Trial, the women would not give the telephone to them during the recruitment calls. Therefore, in the retention study, the intervention was designed to include female spouses/partners in order to garner their support for the project, and to potentially serve to help retain the men in the study. For example, during each telephone call, the retention coordinator asks to speak with the participant's spouse/partner, if he has one. If the retention coordinator has not spoken previously with the spouse/partner, the retention coordinator then introduces herself and asks if they would like information related to particular topics. If the retention coordinator has spoken previously with the spouse/partner, the retention coordinator follows up on previous conversations, and gives the spouse/partner information they requested.

(e) The retention coordinator maintains computerized files detailing which men have been contacted each month. During the third month of the study, the retention coordinator noted that it would be helpful not only to know which men were called, and which still needed to be called each month but also the time of day and day of the week when the men were reached. The retention coordinator felt that this additional information would assist her in successive months to contact the men during a time when they could be reached. Subsequently, information related to the time of day and day of the week each participant was reached was added to the computerized files.

In summary, the findings of this study can be used to help African American men benefit from the positive aspects of participation in prostate cancer research. The focus group findings will lay the foundation for a future study designed to assess differences in perceptions of cancer screening among African American men of different ages, and to identify potential drop-outs, who could then receive the intensive follow-up provided by a retention coordinator. The study has gone well to date. A number of challenges have been encountered and solutions to these challenges have been proposed.

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## **APPENDIX A**

“African American Men in the PLCO Trial: Developing And Testing  
Methods To Increase Retention”

Consultant Meeting Agenda

May 24-25, 1999

May 24, 1999 (Room 3C08, 8:30 a.m. – 5:00 p.m.)

- I. Introductions
- II. Overview of the Department of Defense-funded study “African American Men In The PLCO Trial: Developing And Testing Methods To Increase Retention”
- III. Study Update
- IV. Description of Remaining Work
- V. Review of the Study Timeline
- VI. Development of Focus Group Questions Assessing Attitudes of African American Men Toward Cancer Screening (Review of Similar Work Conducted at Henry Ford Health System with African American Women to Ascertain the Cultural Appropriateness of A Breast Cancer Risk Factor Survey)

May 25, 1999 (Room 1C00, 8:30 a.m. – 2:30 p.m.)

Development of Focus Group Questions (continued)



## **APPENDIX B**

## SCRIPT FOR AT0 MALE

### INTRODUCTORY TELEPHONE CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. As part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR AT0 MALE

### FIRST MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for \_\_\_\_\_.

more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT0 MALE

### SECOND MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.



STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

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Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR ATO MALE

### THIRD MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

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Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive **this year**? These screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

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## SCRIPT FOR AT0 MALE

### ANNUAL SCHEDULING CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, you have been selected to be in the group of the study that will receive free cancer screening exams. I would like to schedule an appointment so you can take advantage of them.

With this being your first year in the study, your exams will consist of:

- A blood test
- Chest x-ray
- An exam of the prostate
- And a flexible sigmoidoscopy

Since there is preparation involved for your exams, we will send you a packet containing two Fleet enemas and the instructions, a map to the location, and a letter confirming the day, date, time, and location of your appointment.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which of these would be closest to you?

(AFTER DETERMINING THE NEAREST CLINIC)

Because all of the exams are done in the one visit, it will take approximately an hour and a half to two hours for your appointment. Are mornings or afternoons best for you?

Are you available on (day), (date) at (time) at (clinic)?

(AFTER SCHEDULING THE APPOINTMENT), We will be sending you a letter confirming the day, date, and time of your appointment.

I have your address as (address), (street name), (city), (zip code). Is this correct?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, since this is your first time getting these screenings, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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## SCRIPT FOR A T0 MALE

### ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. I'm calling from the PLCO study at Henry Ford Hospital. You have been selected to be in the group of the study that will receive free cancer screening exams. I would like to schedule an appointment so you can take advantage of them.

With this being your first year in the study, your exams will consist of:

- A blood test
- Chest x-ray
- An exam of the prostate
- And a flexible sigmoidoscopy

Since there is preparation involved for your exams, we will send you a packet containing two Fleet enemas and the instructions, a map to the location, and a letter confirming the day, date, time, and location of your appointment.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
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Which of these would be closest to you?

(AFTER DETERMINING THE NEAREST CLINIC)

Because all of the exams are done in the one visit, it will take approximately an hour and a half to two hours for your appointment. Are mornings or afternoons best for you?

Are you available on (day), (date) at (time) at (clinic)?

(AFTER SCHEDULING THE APPOINTMENT), We will be sending you a letter confirming the day, date, and time of your appointment.

I have your address as (address), (street name), (city), (zip code). Is this correct?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, since this is your first time getting these screenings, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T1 MALE

### INTRODUCTORY TELEPHONE CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. As part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T1 MALE

### FIRST MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).



IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, STATE: Mr. \_\_\_\_\_, I have noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you for this! We are interested in what keeps people involved in projects such as the PLCO Trial. What things were helpful to you in getting your scheduled screenings?

WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST, STATE: Mr. \_\_\_\_\_, I see that you did not get your PSA test when you came to our PLCO clinic last year. Was there something that kept you from getting this exam last year?

(PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their PSA test. Was this something that you experienced? What kept you from getting your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THE PSA TEST. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY, STATE: Mr. \_\_\_\_\_, I see that you did not get your chest x-ray when you came to our PLCO clinic last year. Was there something that kept you from getting this exam last year?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY, STATE: Mr. \_\_\_\_\_, I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic last year. Was there something that kept you from getting this exam last year?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM, STATE:  
Mr. \_\_\_\_\_, I see that you did not get your digital rectal exam when you came to our  
PLCO clinic last year. Was there something that kept you from getting this exam last  
year?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their  
digital rectal exam. Was this something that you experienced? What kept you from  
getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT  
SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM.  
STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you  
so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO  
THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO  
SCREENINGS, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in  
the PLCO Trial! Your participation in this project is very important to us. We are  
interested in what keeps people from getting their scheduled PLCO screenings. What  
things kept you from getting your scheduled screenings last year? (PROBE FOR  
BARRIERS.)

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations  
of people. In addition, the findings related to prostate cancer may be particularly  
important to African American men. For these reasons, I would like to work with you to  
help to make your PLCO screenings as easy for you as possible. RESPOND TO THE  
BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive **this year**? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for

more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT1 MALE

### SECOND MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings last year? (PROBE FOR BARRIERS.)

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to



help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

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Do you have any other questions or concerns that you would like to discuss today?  
IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT1 MALE

### THIRD MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

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Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic last year. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings last year? (PROBE FOR BARRIERS.)

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to

help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.



Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

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Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT1 MALE

### ANNUAL SCHEDULING CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, I would like to schedule you for this year's free cancer screening exams.

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum?  
IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE  
AN EXAM OF THAT PLCO ORGAN.

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road , off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S  
NAME, PHONE # AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as (read from the overview). Is that correct? And is your physician Dr. (from the overview) at (address and city)?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

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ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information

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Are any of these things (or other things) a concern for you?

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Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR A T1 MALE

### ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. I'm calling from the PLCO study at Henry Ford Hospital. I would like to schedule this year's free cancer screening exams.

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum?  
IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as (read from the overview). Is that correct? And is your physician Dr. (from the overview) at (address and city)?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.



Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.

IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T2 MALE

### INTRODUCTORY TELEPHONE CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. As part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T2 MALE

### FIRST MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, STATE: Mr. \_\_\_\_\_, I have noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you for this! We are interested in what keeps people involved in projects such as the PLCO Trial. What things were helpful to you in getting your scheduled screenings?

WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your PSA test when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- last year and two years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their PSA test. Was this something that you experienced? What kept you from getting your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THE PSA TEST. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- last year and two years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr. \_\_\_\_\_, I understand what

you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic

- two years ago.

Was there something that kept you from getting this exam

- two years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE-DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your digital rectal exam when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- last year and two years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their digital rectal exam. Was this something that you experienced? What kept you from getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S)-MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps

people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings

- last year
- two years ago
- last year and two years ago?

(PROBE FOR BARRIERS.)

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them



about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT2 MALE

### SECOND MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic

- two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PLCO screenings when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PLCO screenings. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information.



STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

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Do you have any other questions or concerns that you would like to discuss today?  
IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT2 MALE

### THIRD MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

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Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic

- two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PLCO screenings when you came to our PLCO clinic

- last year
- two years ago
- last year and two years ago.

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PLCO screenings. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

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ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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Do you have any other questions or concerns that you would like to discuss today?  
IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.



## SCRIPT FOR AT2 MALE

### ANNUAL SCHEDULING CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, I would like to schedule you for this year's free cancer screening exams.

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum?  
IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road , off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as (read from the overview). Is that correct? And is your physician Dr. (from the overview) at (address and city)?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

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ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.



## SCRIPT FOR A T2 MALE

### ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. I'm calling from the PLCO study at Henry Ford Hospital. I would like to schedule this year's free cancer screening exams.

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum?  
IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as (read from the overview). Is that correct? And is your physician Dr. (from the overview) at (address and city)?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T3 MALE

### INTRODUCTORY TELEPHONE CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. As part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T3 MALE

### FIRST MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).



IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, STATE: Mr. \_\_\_\_\_, I have noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you for this! We are interested in what keeps people involved in projects such as the PLCO Trial. What things were helpful to you in getting your scheduled screenings?

WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

(PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their PSA test. Was this something that you experienced? What kept you from getting your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THE PSA TEST. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago

- two years ago and three years ago
- last year, two years ago, and three years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic

- three years ago.

Was there something that kept you from getting this exam

- three years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your digital rectal exam when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago

- two years ago and three years ago
- last year, two years ago, and three years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their digital rectal exam. Was this something that you experienced? What kept you from getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray (for smokers only), and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT3 MALE

### SECOND MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).



IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
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I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic

- three years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
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I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PLCO screenings when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

(PROBE FOR BARRIERS.)

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PLCO screenings. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray (for smokers only), and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you **also** mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

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Do you have any other questions or concerns that you would like to discuss today?  
IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT3 MALE

### THIRD MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

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IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

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- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
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Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PLCO screenings. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

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ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

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Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT3 MALE

### ANNUAL SCHEDULING CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, I would like to schedule you for this year's free cancer screening exams.

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum?  
IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

Have you ever smoked cigarettes, cigars or a pipe on a regular basis for six months or longer? IF NO, DO NOT OFFER OR SCHEDULE THE CHEST X-RAY. IF YES, CONTINUE (OFFER AND SCHEDULE THE CHEST X-RAY.)

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road , off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID, AND INDICATE WHETHER THE PERSON IS A NON-SMOKER OR A SMOKER.)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as (read from the overview). Is that correct? And is your physician Dr. (from the overview) at (address and city)?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).



Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you **also** mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?  
IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR A T3 MALE

### ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. I'm calling from the PLCO study at Henry Ford Hospital. I would like to schedule this year's free cancer screening exams.

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum?  
IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

Have you ever smoked cigarettes, cigars or a pipe on a regular basis for six months or longer? IF NO, DO NOT OFFER OR SCHEDULE THE CHEST X-RAY. IF YES, CONTINUE (OFFER AND SCHEDULE THE CHEST X-RAY.)

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID, AND INDICATE WHETHER THE PERSON IS A NON-SMOKER OR A SMOKER.)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as (read from the overview). Is that correct? And is your physician Dr. (from the overview) at (address and city)?

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).



Mr. \_\_\_\_\_, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T4 MALE

### INTRODUCTORY TELEPHONE CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. As part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T4 MALE

### FIRST MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, STATE: Mr. \_\_\_\_\_, I have noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you for this! We are interested in what keeps people involved in projects such as the PLCO Trial. What things were helpful to you in getting your scheduled screenings?

WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their PSA test. Was this something that you experienced? What kept you from getting your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THE PSA TEST. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your

chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic

- four years ago.

Was there something that kept you from getting this exam

- four years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_\_ kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your digital rectal exam when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago.

Was there something that kept you from getting this exam

- last year
- two years ago



- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their digital rectal exam. Was this something that you experienced? What kept you from getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
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(PROBE FOR BARRIERS.)

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT4 MALE

### SECOND MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

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IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
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I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

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IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic

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IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

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Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT4 MALE

### THIRD MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

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Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
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- three years ago and four years ago?

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
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IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic

- four years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
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IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PLCO screenings when you came to our PLCO clinic

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- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago.

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. **RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.**

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you **also** mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT4 MALE

### ANNUAL SCHEDULING CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, I would like to schedule you for this year's free cancer screening exam.

First, I would like to ask . . . Have you been diagnosed with cancer of the prostate, lung, colon or rectum?

IF NO, CONTINUE. IF YES, CONTINUE AND RECORD RESPONSE ON THE OVERVIEW AND ON THE SCHEDULE.

This year we would like to schedule you for a blood test only, and the appointment should be approximately 15 minutes.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE BLOOD AND X-RAY ONLY SLOT, ON THE OVERVIEW, PARTICIPANTS NAME, PHONE # AND PID #.)

We will send a letter confirming the day, date, time, and the location with a map . . .

IF NO PROSTATE OR IF CANCER IS REPORTED OF THE PROSTATE – NO RESULTS ARE MAILED. . . SKIP TO ADDRESS INFORMATION.

. . . and after the exam is done we will send a copy of the results to both you and your physician. We have your physician as Dr. (from the overview) at (address and city). Is that correct?

We have your address as (read from the overview). Is that correct?

Mr. \_\_\_\_\_, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.



After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you **also** mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR A T4 MALE

### ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. I'm calling from the PLCO study at Henry Ford Hospital. I would like to schedule this year's free cancer screening exams.

First, I would like to ask . . . Have you been diagnosed with cancer of the prostate, lung, colon or rectum?

IF NO, CONTINUE. IF YES, CONTINUE AND RECORD RESPONSE ON THE OVERVIEW AND ON THE SCHEDULE.

This year we would like to schedule you for a blood test only, and the appointment should be approximately 15 minutes.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road , off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE BLOOD AND X-RAY ONLY SLOT, ON THE OVERVIEW, PARTICIPANTS NAME, PHONE # AND PID #.)

We will send a letter confirming the day, date, time, and the location with a map . . .

IF NO PROSTATE OR IF CANCER IS REPORTED OF THE PROSTATE – NO RESULTS ARE MAILED. . . SKIP TO ADDRESS INFORMATION.

. . . and after the exam is done we will send a copy of the results to both you and your physician. We have your physician as Dr. (from the overview) at (address and city). Is that correct?

We have your address as (read from the overview). Is that correct?

Mr. \_\_\_\_\_, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.



After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T5 MALE

### INTRODUCTORY TELEPHONE CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. As part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

## SCRIPT FOR A T5 MALE

### FIRST MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, STATE: Mr. \_\_\_\_\_, I have noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you for this! We are interested in what keeps people involved in projects such as the PLCO Trial. What things were helpful to you in getting your scheduled screenings?

WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your PSA test when you came to our PLCO clinic

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- two years ago
- three years ago
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Was there something that kept you from getting this exam

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(PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their PSA test. Was this something that you experienced? What kept you from getting your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THE PSA TEST. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your chest x-ray when you came to our PLCO clinic



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- three years ago
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Was there something that kept you from getting this exam

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PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic

- five years ago.

Was there something that kept you from getting this exam

- five years ago?

PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I see that you did not get your digital rectal exam when you came to our PLCO clinic

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- four years ago
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Was there something that kept you from getting this exam

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PROBE FOR BARRIERS: Sometimes people say that \_\_\_\_ kept them from getting their digital rectal exam. Was this something that you experienced? What kept you from getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM. STATE: Mr. \_\_\_\_\_, I understand what you are saying. I would like to work with you so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING,

STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings

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(PROBE FOR BARRIERS)

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive **this year**? Again, these screenings will consist of the PSA test and a flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.

Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT5 MALE

### SECOND MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.



STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

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I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

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I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic

- five years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic

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- four years ago and five years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PLCO screenings when you came to our PLCO clinic

- last year
- two years ago
- three years ago

- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
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- two years ago and three years ago
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- two years ago and four years ago
- two years ago and five years ago
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- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PLCO screenings. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive **this year**? Again, these screenings will consist of the PSA test and the flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you **also** mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?  
IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.



## SCRIPT FOR AT5 MALE

### THIRD MONTH

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr. \_\_\_\_\_, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
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- last year, three years ago, and five years ago
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- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
- last year, three years ago, four years ago, and five years ago
- last year, two years ago, three years ago, and four years ago
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I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic

- five years ago.

I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, when we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your digital rectal exam when you came to our PLCO clinic

- two years ago
- three years ago
- four years ago
- five years ago
- two years ago, three years ago, four years ago, and five years ago
- two years ago, four years ago, and five years ago
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IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. \_\_\_\_\_, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned \_\_\_\_\_, that kept you from getting your PLCO screenings when you came to our PLCO clinic

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Mr. \_\_\_\_\_, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that \_\_\_\_\_ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. \_\_\_\_\_, do you have any questions about any of the PLCO screenings you will receive **this year**? Again, these screenings will consist of the PSA test and a flexible sigmoidoscopy.

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IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

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IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you **also** mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Ms. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR AT5 MALE

### ANNUAL SCHEDULING CALL

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.

Mr. \_\_\_\_\_, I would like to schedule you for this year's free cancer screening exam.

First, I would like to ask . . . Have you been diagnosed with cancer of the prostate, lung, colon or rectum?

IF NO – CONTINUE. IF YES, DO NOT SCHEDULE AN EXAM OF THAT PLCO ORGAN.

Have you had a colonoscopy within the last year, or do you plan to have one soon?

IF NO – CONTINUE. IF YES – DO NOT SCHEDULE THE SIGMOIDOSCOPY AND SCHEULE IN BLOOD/X-RAY SLOT.

This year, your appointment will consist of:

- A blood test
- And the flexible sigmoidoscopy

That is the exam of the lower colon and there is preparation involved, so we will send you a packet containing two Fleet enemas and the instructions. We ask that you eat lightly the night before and the morning of your appointment. It will take approximately an hour and a half to two hours to prepare before you leave your house. The appointment will take approximately an hour and a half to two hours because all of the exams are done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which of these is the most convenient for you?

At the (designated clinic) I have day, month and date at time in the morning or time in the afternoon. Which is best for you?

RECORD IN SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID#.

As I mentioned, we will send the letter confirming the day, date, time and location, a map to the location and the Fleet enemas with the instructions.

Is your address (read from the overview)?

After your exams are done, a copy of the results will be sent to both you and your physician, is that still Dr. (read from the overview), (address)?

Mr. \_\_\_\_\_, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test and the flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call. Our number is 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. \_\_\_\_\_, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

Mr. \_\_\_\_\_, you mentioned \_\_\_\_\_. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

ASK: Mr. \_\_\_\_\_, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.

IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. \_\_\_\_\_? My name is \_\_\_\_\_. How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. \_\_\_\_\_, when we talked last month, you mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about \_\_\_\_\_. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. \_\_\_\_\_, I will call you back later with additional information.



STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

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Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO-CAN HELP TO ADDRESS THOSE CONCERNS).

IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:

While I have you on the telephone, Ms. \_\_\_\_\_, let me check my files to find some information about \_\_\_\_\_. Here it is. There is an agency, \_\_\_\_\_, that helps to \_\_\_\_\_. I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: \_\_\_\_\_. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. \_\_\_\_\_.

Do you have any other questions or concerns that you would like to discuss today?

IF NOT, STATE: It has been nice talking with you today, Ms. \_\_\_\_\_. If you have any questions, please write them down so that we can talk about them next month.

## SCRIPT FOR A T5 MALE

### ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr. \_\_\_\_\_? My name is \_\_\_\_\_. I'm calling from the PLCO study at Henry Ford Hospital. This is your final year of the free cancer screening exams and I would like to schedule your appointment, so that you may take advantage of them.

First, I would like to ask . . . Have you been diagnosed with cancer of the prostate, lung, colon or rectum?

IF NO – CONTINUE. IF YES, DO NOT SCHEDULE AN EXAM OF THAT PLCO ORGAN.

Have you had a colonoscopy within the last year, or do you plan to have one soon?

IF NO – CONTINUE. IF YES – DO NOT SCHEDULE THE SIGMOIDOSCOPY AND SCHEULE IN BLOOD/X-RAY SLOT.

This year, your appointment will consist of:

- A blood test
- And the flexible sigmoidoscopy

That is the exam of the lower colon and there is preparation involved, so we will send you a packet containing two Fleet enemas and the instructions. We ask that you eat lightly the night before and the morning of your appointment. It will take approximately an hour and a half to two hours to prepare before you leave your house. The appointment will take approximately an hour and a half to two hours because all of the exams are done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which of these is the most convenient for you?

At the (designated clinic) I have day, month and date at time in the morning or time in the afternoon. Which is best for you?

RECORD IN SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME,  
PHONE # AND PID#.

As I mentioned, we will send the letter confirming the day, date, time and location, a map  
to the location and the Fleet enemas with the instructions.

Is your address (read from the overview)?

After your exams are done, a copy of the results will be sent to both you and your  
physician, is that still Dr. (read from the overview), (address)?

Mr. \_\_\_\_\_, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test and the flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. \_\_\_\_\_, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call. Our number is 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. \_\_\_\_\_, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

- Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr. \_\_\_\_\_, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.

Hello, Ms. \_\_\_\_\_? My name is \_\_\_\_\_. I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr. \_\_\_\_\_. When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

**SCRIPTS USED WHEN A MESSAGE MUST BE LEFT BECAUSE THE  
TARGET PERSON IS NOT AVAILABLE**



## INTRODUCTORY TELEPHONE CALL

Hello, my name is Vernetta Randolph. As part of a research project to help people in the PLCO Study receive their free cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to questions your or your family may have about things such as Social Security, Medicare, health issues, Head Start or other concerns.

Each call will last at least five minutes.

I will make every attempt to provide you with the information or resources that you and your family request.

Again, my name is Vernetta Randolph. Please call me at 313-874-6228. Thank you. I look forward to hearing from you soon.

## **FIRST MONTH FOLLOW-UP**

Hello, my name is Vernetta Randolph. When I called you recently, I let you know that as part of a research project to help people in the PLCO Study receive their free cancer screenings, I have been assigned to assist you in receiving your screenings. As I stated, I would like to call you on a monthly basis to serve as a resource person, to help to find answers to questions your or your family may have about things such as Social Security, Medicare, health issues, Head Start or other concerns.

Each call will last at least five minutes.

I will make every attempt to provide you with the information or resources that you and your family request.

Again, my name is Vernetta Randolph. Please call me at 313-874-6228. Thank you. I look forward to hearing from you soon.

## SECOND MONTH FOLLOW-UP

Hello, my name is Vernetta Randolph. When I called you recently, I let you know that as part of a research project to help people in the PLCO Study receive their free cancer screenings, I have been assigned to assist you in receiving your screenings. As I stated, I would like to call you on a monthly basis to serve as a resource person, to help to find answers to questions your or your family may have about things such as Social Security, Medicare, health issues, Head Start or other concerns.

Each call will last at least five minutes.

I will make every attempt to provide you with the information or resources that you and your family request.

Again, my name is Vernetta Randolph. Please call me at 313-874-6228. Thank you. I look forward to hearing from you soon.

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## **APPENDIX C**

Listing of Community Resources  
Used in the Retention Study

ADULT DAY CARE

Respite Care  
Care For People With Developmental Disabilities

ADULT WELL BEING BUTZEL CENTER

Seniors  
Empowerment Zone,  
Movies, Picnic, Field Trips  
Aarp Materials  
Assistance With Cost  
Counseling  
Health Screenings and Health Lectures  
Legal Services  
Medicare and Medicaid Assistance  
Support Groups  
Transportation  
Other Activities  
Aerobics, Friendship, Games, Needle Craft, Quilting  
Business Cards for Seniors  
Computer Classes  
Food through Focus Hope Food Program  
Grandparent Legal Assistance  
Prescription Medications  
Substance Abuse Prevention Service

AIDS INFORMATION

How AIDS Is Contracted and How It Can Be Prevented

ALZHEIMER'S

Alzheimer's Association of Michigan Detroit Chapter  
Educational Program  
Helping Hands Respite Care Safe Return Fact Sheet  
Kids and Alzheimer's Disease  
Library List  
Phases of Dementia  
Program Summary  
Publication Order Form  
Support Group  
Things Not To Say to Caregiver

## AMERICAN DIABETES ASSOCIATION

### American Diabetes Association

- Diabetes Information and Action Line
- Diabetes Advocacy
- Diabetes Diagnosis
- Diabetes Facts
- Diabetes Resource Catalog
- First Things First
- Genetics of Diabetes
- Healthy Eating
- Standards of Care
- What is Type I Diabetes?
- What is Type II Diabetes?

## AMERICAN CANCER SOCIETY

### Community Connection

## AMERICAN HEART ASSOCIATION PAMPHLETS

- Cholesterol and Your Heart
- Easy Food Tips For Heart-Health Eating
- Exercise
  - Exercise Diary
- Heart Attack and Stroke: Signals and Action
- High Blood Pressure
- How Can I Monitor My Weight and Blood Pressure?
- How Can I Reduce High Blood Pressure?
- Managing Your Weight
- Now You're Cookin'
- Nutrition
  - Nutrition for Fitness
  - Nutrition Nibbles
- Sodium and Blood Pressure
- Spring/Summer 1999 Catalog Professional and layperson training solutions
  - 1-800 numbers
- Stroke and Heart Attack
- Walking for a Healthy Heart
- What Are Stroke and TIA?
- What You Should Know About Stroke
- What is Your Risk of Brain Attack?
- What's Your Risk of Heart Attack?
- 1999 Heart and Stroke Statistical Update
- Why Should I Limit Sodium?

## AMERICAN LUNG ASSOCIATION

- Facts about Lung Cancer
- Facts in Brief about Lung Disease
- How to Keep Your Lungs Healthy
- The Decision is Yours
- The Lung Cancer Resource Center

## AREA AGENCY ON THE AGING

- Detroit Area Agency on Aging 1999 Directory Eldercare Services

## CANCER INFORMATION

- American Cancer Society
- Barbara Ann Karmanos Cancer Institute
- Breast Cancer
- Breast Cancer Questions and Answers
- Cancer Facts and Figures for African Americans 1998-1999
- Cancer Facts for Women
- Cancer Facts for Men
- Colon and Rectum Cancer
- Colorectal Cancer
- Guidelines for the Early Detection of Cancer
- Healthfinder Questions and Answers
- National Institutes of Health
- Newsletter: The Health Source
- Prostate Cancer: Facts on Prostate Cancer, Testing For Prostate Cancer
- Resource Guide
- Taking Time Support for People with Cancer and the People Who Care About Them
- What You Need To Know about Cancer of the Colon and Rectum
- What You Need To Know about Lung Cancer

## CHILD CARE

- Child Care Centers

## COMMUNITY HEALTH AWARENESS

### AIDS/HIV

- AIDS Fraud Alert
- AIDS: What Women Need To Know
- Coping with HIV/AIDS
- Community Prescription Service
- Dental Health Matters
- Michigan Jewish AIDS Coalition
- Pocket Reference Guide
- What You Should Know About Videx (didanosine), DDL and HIV
- Case Management
- Certified Church Partner
- Community Awareness Group
- Gay, Lesbian, Bisexual Transgender Community
- Breast Cancer Self Examination

## COMMUNITY RESOURCE LIST

Advocacy Services Directory

Child Care Coordinating Council of Detroit/Wayne County Directory of Resources for Children and Family

City of Detroit Directory

Detroit Area Hospital Resource List

Detroit Public Library

Michigan Department of Community Health Maternal and Infant Health

Michigan Senior Resource Directory Community Action Agency Index

State of Michigan Family Independence Agency

## COMMUNITY SERVICES AND PROJECTS

Bankruptcy Guide

Chiropractic Guide

Christian Credit Counselors

Cosmetic Surgery

Criminal Law

Dental Guide

Detroit Housing Commission Resident Selection Office Application and Placement Process

Education Guide

General Health

General Legal

Mental Health

MetroMatrix Human Services Local Source

Mortgage Guide

News and Entertainment Updates

Pamphlets and Newsletters

Personal Injury

St. Patrick Senior Center

Social Security and Disability

Women's Health

## DOMESTIC VIOLENCE

The Michigan Coalition Against Domestic Violence

Wayne County Neighborhood Legal Services Domestic Violence Clinic

## EDUCATION

Directory of Health Education Programs - Henry Ford Hospital

Family Road Programs and Educational Classes - Hutzel Hospital

## EMERGENCY ASSISTANCE

Detroit Area Numbers

## EMPLOYMENT

Census 2000

National Indian Council on the Aging



## FAMILY ROAD PROGRAMS

Hutzel Hospital

## FAMILY SUPPORT NETWORK OF MICHIGAN

Family Phone Line

Project Find

The Family Place Mental Health Unit

## FOOD AND NUTRITION

Detroit Agriculture Network

Focus Hope

Hunger Action Coalition of Michigan

## GRIEF AND BEREAVEMENT

Detroit Area Bereavement Centers

Home Health Agencies Henry Ford Hospital

## HABITAT FOR HUMANITY

Habitat for Humanity listing

## HEALTH CORE

Health Core Henry Ford Hospital

## HEALTH EDUCATION CENTER

American Diabetes Society

Breastfeeding

Cancer Information

Depression

Hearing and Aging

Healthy Food

Heart Attacks

Heat Wave information

Menopause

Michigan Fish

Nutrition for Children

Prostate Cancer

Protecting yourself and your baby from sexually transmitted disease

Substance Abuse

Weight Control

What Do I Need to Know about Hepatitis A, B, and C

Work and Family

## HELP FOR YOUTH AND FAMILIES

Baseball Sports Coalition

Covenant House

National Runaway Switchboard

Teen Pregnancy

## HOME HEALTH CARE

Care Management

Home Health Care Services (State of Michigan)

## HOUSING

Senior Housing

State of Michigan Family Independence Agency

## IMMUNIZATION FOR CHILDREN

Child Health Network Immunization Project

Grandparent Immunizing for Tots

Starting Early Wayne County

## INFORMATION OF MEDICAL CONDITIONS

Alzheimer's Disease

American Stroke Association

Angina Pectoris

Asthma

Brain Attack Stroke

Cholesterol Disorders

Congestive Heart Failure

Crohn's Disease

Depression

Diabetes Mellitus

Epilepsy

FAQ

Glaucoma

Gout

Green Tree

Hypertension

Report by Center for Clinical Effectiveness

Various other diseases

## INSURANCE FOR CHILDREN

Detroit Healthy Start Resource Guide

## LEGAL ASSISTANCE

Adult Protective Services Program

Designation of Patient Advocate Form

Domestic Violence Shelter Guide

Durable Power of Attorney for Health Care Henry Ford Hospital

Jewish Home and Aging Services

MediAlert

The Legal Brief - the Black Women's Lawyers Association of Michigan

## MEDICATION ASSISTANCE

Medical Directory  
Referral List

## MEDICAL INSURANCE

1999 Guide Medicare  
AARP  
Medical Assistance Detroit  
Michigan Medical Assistance Program

## MICHIGAN RESOURCE CENTER

1999 Publication Catalog  
1999 Videos for Loan

## RECIPES

Diabetic  
Low Fat

## SMOKING/QUITTING

Facts and Tips for Quitting  
Involuntary Smoking  
Smoking and pregnancy

## SENIOR CENTER BUTZEL

SEE Butzel Center  
Children's Issues

## SOCIAL ACTIVITIES

Exercise  
Cultural Happenings Detroit  
Detroit Public Library  
1999 Wayne County Parks Schedule  
1999 Summer Activities Guide

## SOCIAL SECURITY

Understanding the Benefits

## SUBSTANCE ABUSE

Boniface Intensive Outpatient Day Treatment  
Michigan Department of Community Health

## TEMPORARY SHELTER

"C-O-T-S"

## THE SENIOR ALLIANCE AREA AGENCY ON AGING

Programs  
Senior's Guide <http://www.aaalc.org>

## TRANSPORTATION

Department of Transportation of Detroit Seniors Services

Health Transportation

Specialized Transportation

## UNITED WAY

Community Services

Guide to Health and Human Services

Resources for Community Problem Solving

Surviving Unemployment